Using Ecological Momentary Assessment to Monitor
Community Participation of People with Mobility-Related Disabilities

by

Chiaki Gonda

Submitted to the graduate degree program in Department of Applied Behavioral Sciences and the Graduate Faculty of the University of Kansas in partial fulfillment of the requirements for the degree of Master of Arts.

_____
Chairperson Glen W. White, Ph.D.

_____
Stephen B. Fawcett, Ph.D.

_____
Jomella Watson-Thompson, Ph.D.

Date Defended 6/13/2011

The Thesis Committee for Chiaki Gonda
certifies that this is the approved version of the following thesis:

Using Ecological Momentary Assessment to Monitor
Community Participation of People with Mobility-Related Disabilities

_____

Chairperson Glen W. White, Ph.D.

Date approved: 06/13/2011

Using Ecological Momentary Assessment to Monitor Community Participation of People with Mobility-Related Disabilities

Abstract

Increased community participation of people with disabilities is a goal of many community-based disability organizations. Researchers used an ecological momentary assessment (EMA) approach to investigate factors that might increase community participation of people with mobility-related disabilities. EMA is a measurement method that captures self-report data on participant's behavior and experiences in a community based context. This paper will report on the community participation behavior of five individuals with severe mobility-related disabilities. These individuals each used a personal digital assistant (PDA) device to keep track of their community participation activities. In Study 1, two participants enrolled and received an education and skills training package and weekly peer support meetings. Both participants increased knowledge and skills scores on their posttests by an average of 22.5% (Mick 55-77%) (Don 55-78%), indicating they acquired knowledge and skills taught in the two-day *Get Out & About!* training workshop. One participant slightly increased community participation frequency after training, while the other did not increase community participation over baseline level. Using PDAs to collect and measure target behavior was successful and reliable; however, the PDAs appeared to have a prompting effect. Independent variables for Study 2 included the components of visual and oral feedback, and bus passes to facilitate increased community participation of three participants. In addition, one of the participants also received a review of the study goals as part of his intervention. Study 2 findings suggest that this multi-component intervention package had some effect on increasing frequency and duration of community participation. Overall, these findings support the feasibility and durability of using EMA to continuously measure community participation of people with mobility-related disabilities.

Table of Contents

Figures

Tables

Acknowledgements

I would like to express my sincere gratitude to those who helped make this study possible and successful. First and foremost, I would like to thank Dr. Glen W. White, who has been my advisor since 2005. His guidance and mentorship shaped my professional development and greatly affected my behavior and attitude toward applied research. I also appreciate the many opportunities he has provided me to be involved in research and other professional activities throughout my graduate career. It has been a great learning and rewarding experience for me, and I look forward to continuing our collaborative relationship.

I also appreciate the interest and guidance of my thesis committee members, Dr. Stephen Fawcett and Dr. Jomella Watson-Thompson. I benefited greatly from their ideas and feedbacks.

I would also like to thank the Research and Training Center on Measurement and Interdependence in Community Living (RTC/MICL) at the University of Kansas for their financial and technical support of this study. I am immensely thankful for my colleagues in the Research Group on Rehabilitation on Independent Living, Melissa Gard, Dot Nary and Carol Sella, for their valuable feedback and suggestions. I am so blessed to have such trusted and wonderful colleagues.

In addition to those mentioned above, I extend my special thanks to the RTC/IL staff members and MICL partners for technical and scientific guidance for my study. Finally and most especially, I thank my family, friends, colleagues in the disability community, Justin and Yoshiko Dart, and my fiancé, Kentaro Kotani for caring, cheering and believing in me. I could not have done this without their outpouring support and encouragement.

Community Participation of People with Disabilities

People with disabilities are the largest and fastest growing minorities in the U.S. (Nafukho, Roessler, & Kacirek, 2010). Yet, their issues are often unrecognized and unaddressed. Despite deinstitutionalization and independent living support services, people with disabilities continue struggles to attain basic human rights and equality. Passage of laws such as the Americans with Disabilities Act of 1990 opened doors for people with disabilities to join mainstream society. However, people with disabilities still face community barriers to increase and maintain enhanced participation (White, Simpson, Gonda, Ravesloot, & Coble, 2010). According to the National Organization on Disability and Harris Interactive [NOD/Harris] 2000, people with disabilities report less satisfaction when they do participate in their communities compared to people without disabilities. Many people with disabilities feel "not at all satisfied" with their level of their community involvement and reported being "not at all involved" in their communities (Taylor, 2000). Furthermore, a recent report by Kessler Foundation and NOD/Harris (2010) show that there are significant disparities between people with disabilities and people without across various participation domains. For example, only 21% of people with disabilities have full or part-time jobs compared to 59% of the non-disabled population.

Barriers and Facilitators to Full Participation

Barriers to community participation include not only personal factors such as lack of financial resources (Carpenter, Forwell, Jongbloed, & Backman, 2007) or secondary conditions such as pressure sores and urinary tract infections (Barker, Kendall, Amsters, Pershouse, Haines, & Kuipers, 2009); but also environmental factors such as lack of accessible transportation (Seekins, Enders, Pepper, & Sticka, 2007), public accommodations (Baker & Kaufman-Scarborough, 2001), and housing (Maisel, 2006); and built inaccessible environments (Gray,

Gould, & Bickenbach, 2003). These barriers often lead to discrimination, limited participation, and restricted choice, which often jeopardize the independence of people with disabilities (McClain, Medrano, Marcum, & Schukar, 2000).

Facilitators are enabling features that maximize choice and control of people with disabilities and are more likely to enhance full participation. Facilitators of community participation include safety and accessibility of built environments, information resources, problem solving skills (Hammel, Jones, Gossett, & Morgan, 2006), assistance from other people, accessible transportation, good morale, good weather, good health, appropriate equipment or adaptations, and environmental adaptations (Meyers, Anderson, Miller, Shipp, & Hoenig, 2002).

Even though full participation is an elusive goal, participating in community life carries some positive meaning to the lives of people with disabilities. Hammel, Magasi, Heinemann, Whiteneck, Bogner and Rodriguez (2008) conducted focus group interviews to better understand perceptions and experiences of community participation by people with disabilities. Several themes contributing to participation related values emerged and were identified from the focus group interviews. Figure 1 illustrates the core themes around these participation values.

Participation values are influenced and supported by six interacting dimensions: (a) meaningful engagement and being a part of, (b) personal and societal responsibility, (c) having an impact and supporting others, (d) social connection, inclusion and membership, (e) access and opportunity and (f) choice and control. Respect and dignity are overarching principles that drive and embrace participation values. Each of these dimensions is needed to fulfill and maximize one’s participation profile (Hammel et al., 2008). Even though their focus group interview data showed that there is no clear definition or optimum level of community participation, study

participants expressed participation as “a means to experience social connectedness with other people and communities, pointing to issues of social capital” (pg. 1459).

Figure 1. Qualitative theme areas epitomizing participation (adapted from Hammel, Magasi, Heinemann, Whiteneck, Bogner, & Rodriguez, 2008).

Social Capital and People with Disabilities

Condeluci (2008) defines social capital as “another name for friendship and refers to the connections and relationships that develop around community and the value these relationships hold for the members” (pg. 11). According to Helliwell (2001), people who have a higher level of social capital are more likely to be employed, live longer, and be healthy. Empirical research has demonstrated the importance of social capital on enriching health (Hyyppä & Mäki, 2003) and reducing stress (Herbert & Smith, 1997; Mitchell & Harrison, 2001) for economically disadvantaged and minority populations. Having a higher level of social capital mutually benefits both the individual and the community. One approach to increase one’s social capital is to

participate in community and civic activities (Putnam, 1995). Because people with disabilities are often socially isolated, they are less likely to be involved in their communities. Social isolation threatens the formation and maintenance of networks and associations, which is a vital foundation of building social capital (Chenoweth & Stehlik, 2004). As a result, people with disabilities have fewer opportunities to practice community participation and build social capital.

Community Participation as an Outcome Measure

The notion of increased and full participation holds the interest of constituencies of disability such as grant agencies, policy makers, rehabilitation providers, and advocacy organizations (Hammel et al., 2008). With the newly revised *International Classification of Functioning, Disability and Health (ICF)* (World Health Organization, 2001), community participation is considered to be the "gold standard of outcome measurement in disability and rehabilitation" (Seekins, Ipsen, & Arnold, 2007). Likewise, one *Healthy People 2020* objective outlines increased participation of people with disabilities in social, spiritual, recreation, community and civic activities (U.S. Department of Health and Human Services, 2010). A variety of interventions studies have aimed at increasing knowledge (e.g., Hagglund et al., 2005; Hughes et al., 2003) and developing skills (e.g., Brown, Lewis, & Hurvitz, 2009; Coleman-Martin, & Heller, 2004) to enhance the lives of individuals with disabilities, but many of these studies focus on a specific target behavior or proximal outcomes and do not often measure how the interventions impact fuller community participation of people with disabilities (White, Gonda, Peterson, & Drum, 2011). While these interventions might teach people with disabilities important life skill competencies, people with disabilities also need to gain role competencies and be able to create and maintain important community roles as a "friend, neighbor, consumer, citizen and conserver" (Condeluci, 1999, p. 95). White et al., (2010) refers this as the

interdependence model, where people with disabilities are no longer "mere occupants in *the* community" but are "vital contributors of *their* communities" (pg. 238). Increased community participation is an ultimate indicator that people with disabilities are independent, yet involved and integrated into society. Research that includes community participation outcomes is needed to maximize the effectiveness and generalization of research findings (White et al., 2011). It is important that future research include participation measurements to provide in-depth analyses of individuals and their environmental characteristics.

Research on Measurement of Community Participation

There has been growing attention to and literature on measurement of community participation of people with disabilities addressing the issues of conceptualization (e.g, Dijkers, 1998; Dijkers, 2010), measurement construction (e.g., Gray, Hollingsworth, Stark, & Morgan, 2006), and instrument development (e.g., Gray, Hollingsworth, Stark, & Morgan, 2008). With respect to the measurement of community participation, the researchers have developed assessment tools such as the Craig Handicap Assessment and Reporting Technique (CHART) (Whiteneck, Charlifue, Gerhart, Overhosler, & Richardson, 1992), the Community Integration Questionnaire (CIQ) (Willer, Ottenbacher, & Coad, 1994), the Participation Survey/Mobility (PARTS/M) (Gray et al., 2006), and the Participation and Activity Measurement Systems (PAMS) (Harris, Sprigle, Sonenblum, & Maurer, 2010) to collect data on community participation and activities of people with disabilities. However, many of these surveys are administered to a group of individuals at one point in time and rely on self-reports and an extended periods of recall. While these surveys are valuable in collecting baseline information on community participation, they do not capture how the individual interacts with the environment across time and different life contexts; and therefore ignore the unique experiences and

interaction of individuals (Seekins et al., 2007).Few empirical studies involve interventions to assess and analyze community participation of people with disabilities. White, Paine-Andrews, Mathew and Fawcett (1995) examined the effect of home entrance access modification of mobility device users on their reported community visits. Gray and Dashner (2010) studied the effectiveness of a training program for personal assistance service on community participation of center for independent living (CIL) consumers with disabilities. Newman (2010) used a photo voice strategy to remove community access barriers to promote increased participation of people with spinal cord injury. It is encouraging that the field is refining measurement tools and developing interventions to enhance community participation of people with disabilities. Still, a literature search reveals limited research providing empirical data on increasing community participation of people with disabilities and including dynamic participation measures.

Ecological Momentary Assessment (EMA)

To reduce challenges identified in the literature, this study used a Ecological Momentary Assessment (EMA) approach. EMA is a "method using repeated collection of real-time data on participants' behavior and experience in their natural environment" (Shiffman, Stone, & Hufford, 2008, pg. 3). EMA minimizes recall bias and maximizes ecological validity by sampling a subject's behavior repeatedly across settings and contexts over time in the natural environment where their behavior occurs (Shiffman et al., 2008). EMA involves (a) recording participants' behavior at specified intervals (e.g., random, fixed-time schedule) as defined events occur or do not occur, and (b) assessing different variables (e.g., antecedents, consequences, duration, frequency, latency, intensity) of a target behavior often via electronic devices. EMA is an emerging measurement technique used frequently in the field of behavioral medicine and counseling psychology to treat or examine a wide range of socially significant problems such as

eating disorders (Smyth, Wonderlich, Crosby, Miltenberger, Mitchell, & Rorty, 2001), cigarette smoking (Shiffman et al., 2002), stress-related disease (Yoshiuchi, Yamamoto, & Akabayashi, 2008), fatigue (Curran, Beacham, & Andrykowski, 2004), and insufficient adolescent physical activity (Dunton, Whalen, Jamner, Henker, & Floro, 2007). Seekins et al., (2007) used EMA to study the measurement of community participation. In this study, five individuals with disabilities carried a Personal Digital Assistant (PDA) and were asked to report their community participation status six times daily across 49 days of observation. At each prompt, participants accessed a PDA to enter their current activity status and perceived barriers and facilitators. The survey results yielded a wealth of information about community participation of people with disabilities. The authors noted that PDAs could be useful in measuring naturalistic behaviors and capturing important variables associated with community participation, and suggested that EMA be used to compare and evaluate the intervention effectiveness within and across different disability populations.

Study Overview

The purpose of this study was to: (a) replicate and adapt the study by Seekins et al., (2007) to examine the utility of the EMA method in measuring community participation of people with disabilities, and (b) test the effectiveness of different intervention components to increase community participation of people with mobility-related disabilities.

In Study 1, a combination of educational and skills training and peer support was used as an intervention tool. Educational and skills trainings are common intervention strategies for persons with disabilities (e.g., Balcazar, Seekins, Fawcett, & Hopkins, 1990; Ulincy, Adler, Kennedy, & Jones 2006; White & Vo, 2005). The training manual titled, *Get Out & About!* was developed and used in the training. *The Get Out and About! manual* consists of four chapters on

goal setting, problem solving, information seeking, and advocacy. Peer support was incorporated into the training package to facilitate peer mentoring. Peer support meetings were implemented following the training to discuss participants' progress toward their goal attainment, and to exchange information and thoughts about community participation.

In Study 2, visual and oral feedback was incorporated to facilitate participants' increased community participation. Feedback involves a manipulation of consequent events through a contingent stimulation of a subject's behavior (Hayes & Cone, 1981). Several studies have incorporated feedback techniques to influence behavior change in a variety of populations, settings and topics (e.g., Austin, Weatherly, & Gravina, 2005; Bekker, Cumming, Osborne, Bruining, McClean, & Leland, 2010; Sigurdsson & Austin, 2008). In the current study, both visual and oral feedback was used to inform participants about their community participation progress and to assist participants when setting goals and making plans for each upcoming week. Participants also later received bus passes after each identified transportation as a barrier to community participation during the feedback sessions.

Both studies used an Ecological Momentary Assessment (EMA) approach to measure community participation of people with mobility-related disabilities and to capture participants' data in the natural setting across different phases of the intervention.

Research Questions

The research questions for Study 1 were: (a) What are the effects of a community participation training package ("*Get Out & About!*") on participants' acquisition of knowledge and skills?, and (b) what are the effects of a community participation training package ("*Get Out & About!*") and a weekly peer support meeting on participants' frequency of community participation following the training?

The research question for Study 2 was: What are the effects of visual and oral feedback on increasing frequency and duration of community participation of individuals with mobility-related disabilities?

Study 1

This study assessed the effects of a *Get Out & About!* training package that included a training workshop and weekly peer support meetings on increasing participants' community participation.

Method

Participants. Participants were individuals with physical disabilities who used mobility devices to get around. They were selected from respondents to a local newspaper advertisement and recruitment flyers distributed by a staff member at the local CIL.

Inclusion and Exclusion Criteria. To be included in the study, potential participants had to be: (a) aged 18-65 years, inclusive, (b) using a mobility-device to negotiate the community, (c) able to provide informed consent, and (d) able to secure transportation for attending trainings and meetings. Individuals were excluded if they: (a) were not able to operate data collection devices (i.e., PDA and digital camera); (b) had a full-time job or other social obligations that might prevent participation in study activities; (c) were living in an institution, nursing home or group-home setting; (d) had a self-declared serious health condition (e.g., COPD, emphysema, rheumatoid arthritis), severe secondary conditions (e.g., pressure sores, depression) and/or another disability (e.g., blindness, deafness, memory loss) that would be a potential barrier to completing assigned tasks and activities; (d) were non-English speakers; or (e) had participated in similar research studies or trainings in the past six months.

Participant one, whom we will call “Mick”, was a 47 year-old white single male with cerebral palsy who used a power wheelchair. He had a bachelor’s degree in Sociology, was unemployed, and lived alone in a three-bedroom apartment with the help of personal care attendants for three hours in the morning (8 a.m.–11 a.m.) and three hours at night (8 p.m.–11p.m). He used para transit or dial-a-ride transportation van service during the weekdays as a method of transportation. Para transit is an accessible door-to-door public transportation service for people with disabilities that offers flexible routes and schedules. During the weekend, Mick’s father usually provided transportation with his accessible van.

Participant two, whom we will call “Don”, was a 60 year-old married white male who used a cane and a walker due to a stroke and was partially paralyzed on the left side of his body. He had a bachelor’s degree in engineering, was retired, and lived in his home with his wife and a cat. He owned his own car and drove when going out to the community.

Settings. The study took place in a Midwestern state with a population of approximately 92,000. All community participation activities, including data collection, were conducted in the participants’ natural environments (i.e., participants’ homes, or community locations). Information sessions, PDA training, and the training workshops were conducted in a small meeting room at a university facility. This room included two white boards, a 42-inch flat screen television, computer with printer, desk, and chairs. Peer support meetings were held in a quiet area of a restaurant at a local grocery store close to where both participants lived.

Materials. Participants were provided with a training manual titled, “*Get Out & About*!” (Appendix A). This manual is an adaptation of the *Living Well with a Disability* (LWWD) manual (The Rural Institute, 2009). LWWD program is a health promotion and wellness intervention program which has been empirically validated to reduce limitations due to

secondary conditions and to reduce health care costs (Ravesloot, Seekins, & White, 2005). The LWWD manual consists of 10 chapters on various topics (i.e., goal setting, problem solving, healthy reactions, beating the blues, healthy communication, seeking information, physical activity, eating well, advocacy, and maintenance) and provides step by step information to assist persons living with disabilities to improve their health and well-being, as a way of achieving other life goals. The LWWD manual was used as a foundation and guide for the development of the *Get Out & About!* training manual. It emphasizes community participation more than health-related topics. The manual provides general information on each topic, individual exercises, and group discussions topics; it also explains how to achieve chapter objectives. Training topics were determined by feedback from several persons with disabilities who participated in a focus group that was convened before the training package was developed. A draft copy of the *Get Out & About!* manual was reviewed by three external reviewers with disabilities for content validity. These reviewers were provided with evaluation forms and were asked to complete the form and provide suggestions and comments (see Appendix B).

Equipment. The Treo Handspring Visor Pro Personal Digital Assistant (Palm, Inc., Sunnydvle, CA) was used to collect data regarding participants' community participation. Participants were asked to carry the PDA and enter data on their activity when the device issued an audible signal. The PDA was programmed using Pendragon Forms 5.1, a software program designed for survey research using Palm OS/Garnet devices and Windows Mobile 5/6/6.5 handheld devices (Pendragon Software, 2010). A research staff member and a volunteer staff with a mobility-related disability pre-tested the PDA device, method, and measures before the study. Each participant received a brief PowerPoint presentation and accompanying handbook

describing protocols on accessing the device and entering data (Appendix C). PDA technical assistance and consultation was available throughout the study.

A Sanyo digital camera (Model VPC-E1090, http://us.sanyo.com/) was used by participants to photograph their community participation activities and/or locations (e.g., park, public sidewalk, trail, etc.) if and when a permanent product (e.g., sales receipts, ticket stubs, medical appointment cards, brochures, etc.) was not available. Each participant received a digital camera, charger, a camera case and a memory card to perform this task for use during the study.

Incentives. Participants received a monetary reward at the end of the study. The reward amount was contingent upon participants' completion of PDA data entries. If a participant's PDA completion rate was more than 90% throughout the study, the participant received the full monetary reward of $250. If the participant's PDA completion rate was between 70-89%, the participant received half of the available reward ($125). If the participant's PDA completion rate was below 70%, the participant received one-fourth of the available reward ($62.50). Participants could receive an additional $5 for each training session and peer support meeting they attended. These additional incentive amounts were added to their final payment. The monetary rewards were withheld until the end of the study to avoid the possible reinforcer value of money as an unintended independent variable to increase the participants' community participation.

Experimental Design

This study used an ABCDC single-subject design with the five phases being: (a) pre-baseline, (b) baseline, (c) post training and peer support, (d) post training and no peer support, and (e) post training and peer support. This design was used to test the acquisition of skills from

use of the *Get Out & About!* workshop and the effects of a training package and peer support intervention on increased frequency of community participation.

Independent Variables. The *Get Out & About!* training package included two components to increase and enhance community participation of individuals with mobility-related disabilities. These components are described below.

***Get Out & About! Training Workshop*.** Participants attended two five-hour training sessions over a period of two days. The *Get Out & About!* workshop is an educational and interactive training to teach consumers skills on how to enhance their community participation using a goal-oriented approach. Skills taught in the training sessions were: (a) goal setting, (b) problem solving, (c) information seeking, and (d) advocacy. Training sessions consisted of PowerPoint presentations, individual exercises and group discussions.

***Weekly peer support meetings*.** Following the training, participants attended a weekly peer support session to report on their progress toward reaching their goals and to discuss barriers or problems they encountered. Peer support is an effective method to facilitate and empower individuals with disabilities to bring about desired social or personal change by sharing emotional and instrumental support (Mead, Hilton, & Curtis, 2001; Solomon, 2004). Peer support, or peer counseling, is a foundation of the disability rights movement, and a pillar of independent living philosophy (Oxford & McDonald, 1999) and is one of core four services offered at the CILs. Peer support was an essential component of the success of the LWWD program (Ravesloot, Seekins, Cahill, Lindgren, Nary, & White, 2006).

The procedures for implementing the independent variables will be described in greater detail later.

Dependent Variables. Several measures were used to assess behavioral change with the intent of demonstrating functional control.

Get Out & About! training pre and posttest. Study participants took a paper and pencil pre-test one week before the training. A posttest was administered following the completion of training. Each test was worth 15 points except for the chapter three test on Information Seeking, which was worth 20 points (Appendix D). These tests included two components: knowledge and skill application. The knowledge section of the test consisted of multiple choice, fill-in-the-blank, matching, and true or false questions. The skill application section of the test included short answer questions to elaborate on participants' understanding of skills taught during the training.

Number of discrete places visited per day. In this study, community participation was defined as one discrete event executed: (a) outside of the participants' homes and/or property, and (b) within 50 miles of the participants' homes. For example, if a participant went to a theater to see a movie and stopped by the grocery store to shop on the way home, this would count as two discrete community participation activities. It was not considered as community participation if the participant had traveled out-of-state trip for a vacation. Data regarding discrete places visited were logged into PDA devices by participants. The devices emitted a signal that prompted participants to enter data four times per day, at the end of each three hour period between 12 p.m. and 9 p.m. Following each prompt participants accessed the PDA and answered a brief six-question survey on their community participation activities in the past three hours.

Cumulative number of action steps, objectives and goals accomplished. During the peer support meeting, participants self-reported progress on action steps, objectives and goals they worked on since the last meeting.

Procedures

The researcher obtained permission from the University of Kansas Human Subjects Committee-Lawrence campus to conduct the study.

Focus group. To further investigate community participation of people with disabilities, the study researchers met with a group of local CIL consumers and conducted a focus group as a preliminary planning for the study. Participants were recruited through flyers, handouts, email messages, word-of-mouth by staff members at the local CIL, and personal contact by the researchers. Six CIL consumers and a sign language interpreter attended the two-hour long focus group session in a conference room at the local CIL. After signing the consent form (Appendix E), participants completed the close-ended survey questions (Appendix F) and engaged in a facilitated discussion (Appendix G) to express their positive experiences and their concerns or frustration regarding their personal community participation experiences. The conversation was recorded with participants' permission using both a audio cassette tape-recorder and a audio digital recorder for redundancy. Two CIL staff members and three research staff members were present at the focus group to assist with consent forms, survey completion, and note taking. Participants each received a $30 gift card for attending the focus group.

Recruitment. An ad in a local newspaper and a local CIL staff member informed the general public and CIL consumers about the study (Appendix H). Thirteen prospective study participants contacted the researchers by phone if they were interested in enrolling in the study. The researcher then conducted a screening phone survey (Appendix I) to assess their initial eligibility. Following the screening phone survey, the researcher contacted those who met the initial eligibility criteria and scheduled a study information session. Of seven individuals who met the initial eligibility criteria, five individuals agreed to attend the information session.

During the information session, the researcher provided a brief overview of the study, and asked the participants to practice using the PDA, and to fill out the pre-enrollment survey (Appendix J). Individuals received $5 restaurant gift cards for attending the information session. Based on the information session interview and pre-enrollment survey results, two individuals (and one alternate participant) were selected to participate in the study and were notified of their enrollment status via surface mail and email. Those who did not meet the criteria were notified of their non-eligibility via surface mail and provided information about the LWWD training workshop available through their local CIL. It was important for non-eligible participants to not feel discouraged and receive another opportunity to enhance their community living.

PDA training. Participants attended PDA training to: (a) learn more about the study, (b) complete the consent form approved by University of Kansas Human Subject Committee (Appendix K), (c) operate and enter practice data on the PDA, (d) use the digital camera, and (e) take a PDA mastery test at the end of the training. After both participants signed the consent, the researcher gave a PowerPoint presentation on PDA operation and data entry with a thorough explanation of item content. Participants were also taught how to use the digital camera with examples and non-examples and practiced taking photographs with the camera. Participants took a paper and pencil test (Appendix L) to determine their mastery of the PDA data entry process at the end of the training session. This test consisted of five questions and participants were asked to choose the best answers based on the scenarios presented. The researcher reviewed responses with the participants and provided feedback and correct answers where needed. Each participant also received a brief PDA handbook and protocol manual. Both participants left the training with a PDA and a digital camera.

Pre-baseline via written self-report. During the PDA training session, participants were asked to complete the community participation activity form (Appendix M) to retrospectively self-report their community participation activities in the past seven days.

Baseline via PDA self-monitoring. Immediately following the PDA training, each participant carried a PDA which had been pre-programmed to signal four times a day at 12 p.m., 3 p.m., 6 p.m., and 9 p.m. At each prompt, participants accessed their PDAs and answered a short survey. The six questions and one reminder page were programmed into the PDA and answered by each participant when prompted. Table 1 presents an overview of the community participation questionnaire and response options for each category.

If the prompt occurred during an important event, conversation, or emergency situation, participants were instructed to use their best judgment in determining whether data entry was appropriate. If participants missed the data entry during those situations, they were asked to enter data as soon as they were able to do so. PDAs were programmed to make two reminder alarms every five minutes then cease prompting for that time interval.

Data retrieval. The researcher visited participants' homes twice weekly (except when the participant/researcher was unavailable) and conducted PDA feedback sessions. The participants were then given another PDA which was ready to store new data. During this visit, the researcher provided feedback to participants regarding their PDA completion performance and asked questions regarding the activity purpose and content using structured scripts (Appendix N). The researcher also exchanged the memory cards containing photos in the cameras and replaced it with a newly-formatted card. Each visit lasted between 15-20 minutes.

Table 1. Community Participation Survey Questions and Answering Options (adapted from Seekins, Ipsen, & Arnold 2007).

Frequency	Location	Activity	Social Context	Duration	Satisfaction	Reminder
Did you go out in the past 3 hours?	Where did you go in the past three hours?	What kind of activity (or activities) did you engage in?	Who were you primarily doing this activity with?	How long were you out in the community?	On a scale of 1-5, how would you rate satisfaction with this activity?	Make sure to keep your permanent products associated with your outings!
Yes No	Entertainment facility Grocery/Drug Store Gym or exercise facility Health care facility Home Office building Park/forest/lake Public sidewalk Religious facility Restaurant/café/bar Retail store School Someone else's home Other	Education Employment Household chores Leisure Social Self-care Resting Transportation Other	Alone Business Person Family Friends Significant other Mixed group Peers or coworkers Pet(s) Professionals Significant other Strangers Other	Less than 30 min. 30 min. to 1 hour 1 hour to 2 hours 2 hours to 3 hours N/A (didn't go out)	1= dissatisfied 2 = slightly dissatisfied 3= neutral 4 = slightly satisfied 5= satisfied	Yes No

The researcher then took the PDA to the research office and retrieved data from it for data analysis. These data were entered into a spreadsheet and analyzed to gain an understanding of participants' community participation activities. This spreadsheet allowed the researcher to monitor: (a) the date and time of survey completion, (b) whether or not participants had gone out during the four three-hour reporting periods each day, (c) activity locations, (d) activity types, (e) social context of activities, (f) duration of activities, and (g) satisfaction with engaged activities. Data stored on the memory card from the digital camera was also uploaded to a computer and saved, and the researcher checked on the date, time, and place where photos were taken, to verify that they corresponded to the date and times that activities were reported.

Verification of self-reports. Throughout the study, participants were asked to save any permanent products associated with their outings (e.g., sales receipts, ticket stubs, medical appointment cards, brochures, etc.). Participants were also asked to photograph their activities and/or locations (e.g., parks, public sidewalks, etc.). The digital camera was used when permanent products could not be obtained. Permanent products were given to the researcher at each data collection meeting and the researcher compared these verification items with participants' self-reported data.

Training. Participants received a "*Get Out & About!*" training manual one week before the training date and were asked to review the manual before attending the training sessions. Two five-hour *Get Out & About!* training workshops were conducted over a period of two days. The training session started at 10 a.m. and ended at 3 p.m. with a one hour working lunch between the morning and afternoon session. The goal setting and problem solving skills chapters were taught on the first day of the training, which began with an introduction of the training and emphasized how to develop a meaningful goal to create a new lifestyle, and to overcome difficulties that might prevent participants from reaching their goals. During the first day of the training, participants developed a goal, three objectives, and a list of action steps for each objective. On the second day of the training, the information seeking and the advocacy skills chapters were taught. The information section focused on the importance of searching for different options and staying informed to achieve goals while the advocacy section educated participants about the power of advocacy and how and when to use it strategically.

The researcher gave a PowerPoint presentation (Appendix O) and facilitated the training using guidelines (Appendix P) and checklist to maintain treatment integrity (Appendix Q). The

entire training was recorded using a digital audio recorder for data analysis, to allow for independent observer reliability for treatment integrity.

Pre and posttest. Pretests were administered a week before the training at each participant's home during a data collection meeting. Don completed the test himself, but Mick asked the researcher to read the questions and record his responses. The posttest was administered immediately after the end of the last training session. Both participants took the test together in a meeting room at a university building.

Weekly peer support meetings. Following the training, participants were asked to attend a weekly peer support meeting. The researcher used a script (Appendix R) to facilitate the discussions. During each meeting, both participants reported their progress on action steps, objectives and goals accomplished. They also discussed facilitators, problems and barriers encountered in reaching their goals. Peer support sessions allowed the participants to elaborate and exchange ideas, and provide advice to help reach their goals. At the end of the peer support session, participants were encouraged to develop a "to-do" list and were asked to complete tasks on the to-do list before the next peer support meeting. Peer support meetings were recorded using the digital audio recorder. These meetings typically lasted from 15 to 30 minutes.

Social validity survey. Upon completion of the study, each participant was asked to independently complete a social validity survey (Appendix S). Yes/No questions and a 5-point Likert-type scale (ranging from 1 = very dissatisfied to 5 = very satisfied) were used to gain feedback concerning the training, procedures and overall experiences in the study.

Reliability. Reliability assessments were conducted to check the consistency of the dependent variables measurement and to assess the fidelity of implementation of the independent variables. Independent observers included two graduate students and one undergraduate student.

All independent observers were trained by the researcher before performing reliability checks. Secondary observers received extensive instruction and feedback on reliability performance procedure and how to complete the scoring sheets. Inter-observer agreement was calculated by dividing the number of agreements by the total number of agreements plus disagreements and multiplying by 100 for each participant.

Results

Focus group discussion. Focus group participants expressed that community participation is a way to get their voices heard, connect with others, give back to the community, and educate community about disability issues. None of the focus group participants reported previously receiving educational or skill training related to community participation. These participants showed interest in attending this type of training and commented that it would be beneficial for consumers with disabilities to increase community participation. Their collective testimony confirmed that community participation is an important part of maintaining independence and enhancing their quality of life.

Pre and posttest score. Both participants took a pre and posttest to assess the acquisition of knowledge and skills taught with the *Get Out & About!* training package.

Figure 2 displays Mick's pre and posttest score results. Mick's test score improved significantly with an exception of the goal setting chapter. Mick's overall test score increased 22%, from 55% on pretest to 77% on posttest. Mick scored 63% on his pretest and 53% on posttest on goal setting chapter, with a 10 % decrease. His problem solving chapter test score had a 50% increase moving from 28% on pretest to 78% on posttest. The Information seeking chapter test score had a 16% increase from 59% on pretest to 75% on posttest. Finally, the

Advocacy chapter test score increased noticeably from 66% on pretest to 100% on posttest, with a 34% increase.

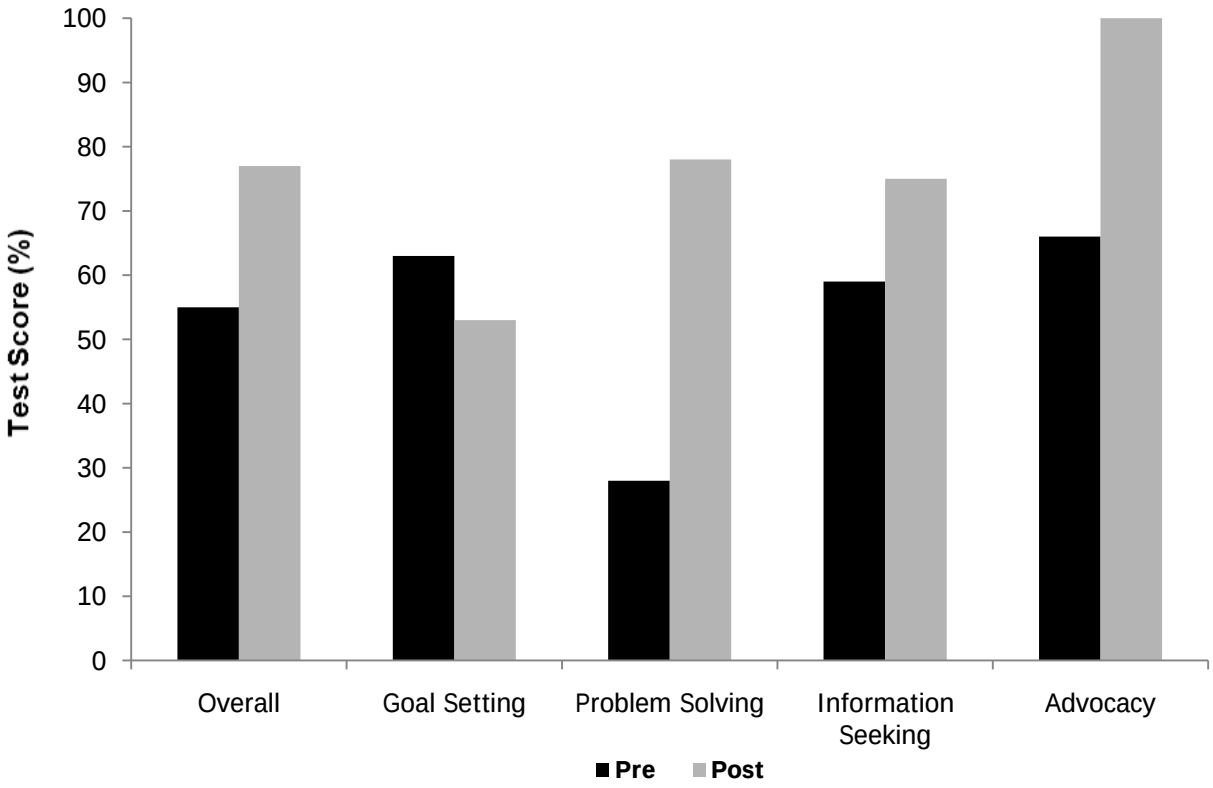


Figure 2. Mick's Pre and Posttest Scores

Figure 3 depicts Don's pre and posttest score results. Don's test score also improved significantly across all chapters except the advocacy chapter. Don's overall test score increased from 55% on pretest to 78% on posttest, a 23% increase. His Goal setting test score increased from 40% on the pretest to 90% on the posttest. Don's Problem solving test score almost doubled from 37% on the pretest to 70% on the posttest. His Information seeking test score increased

from 55% on the pretest to 80% on the posttest, a 25% increase. Finally, Don scored 86% on his pretest and 73% on the posttest on Advocacy chapter.

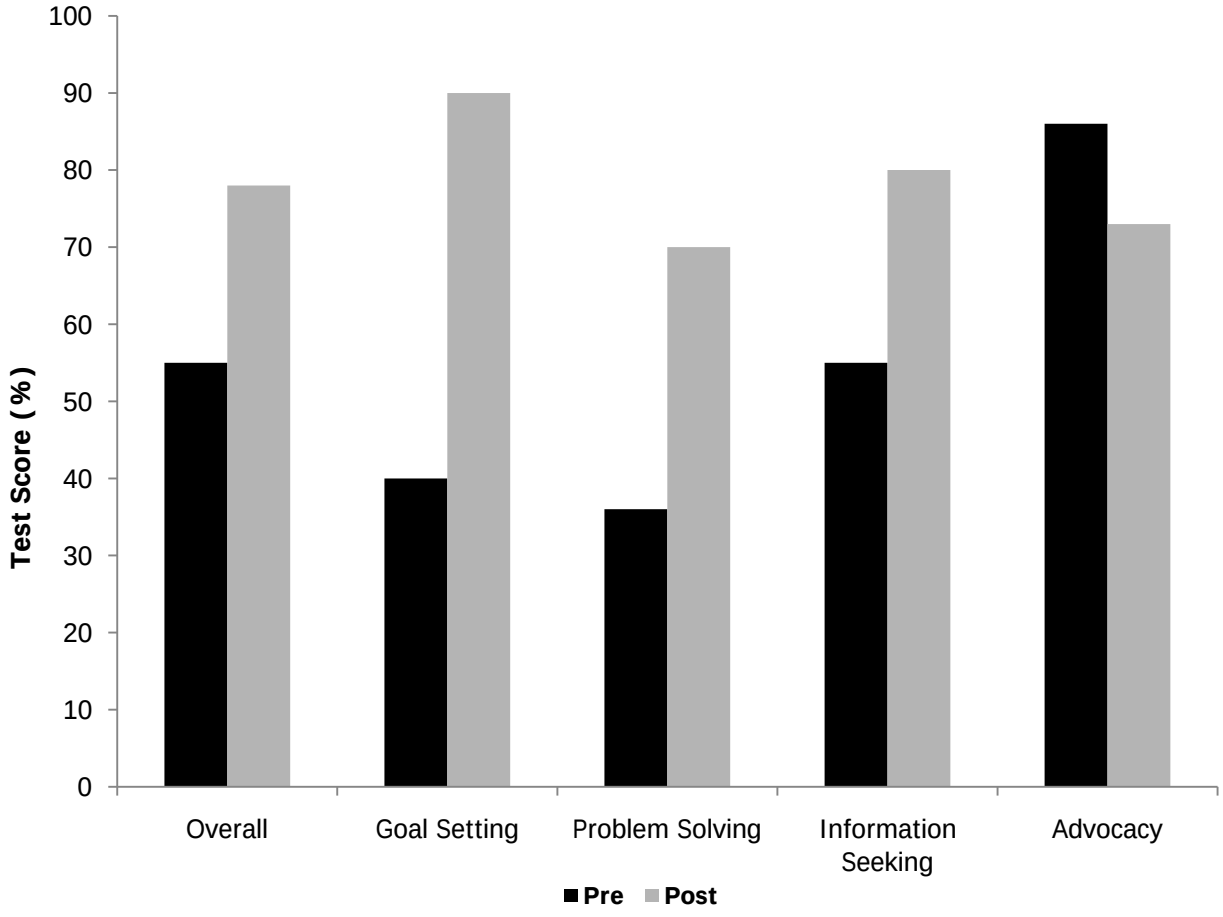


Figure 3. Don's Pre and Posttest Scores

PDA entry completion rate. For Mick, 339 of 348 possible PDA data entries were completed across 87 days of the observation period, with a 97.4% completion rate. For Don, 344 of 345 possible PDA data entries were made across 87 days of the observation period, with a 99.7% completion rate.

Number of discrete places visited per day. Mick experienced a PDA malfunction during the first post training and peer support phase and could not make eight scheduled entries. However, Mick was able to self-report his community participation activities and provide verification from the outings which happened during those two days of PDA malfunction. Aside from this incident, Mick missed only one entry during the entire study period which left him with a 99.7% PDA completion rate. Twelve data entries that were collected during his Colorado trip were not included in the graph since this time away from home (vacation) did not meet the part of the community participation operational definition.

Figure 4 presents the number of discrete places visited in the community by Mick. Mick had an average of 1.25 outings per day during the pre-baseline condition. His daily community participation rate almost doubled to 2.37 outings per day during the baseline condition. During the post training and the first peer support condition, Mick's daily community participation rate averaged 1.54 outings. When peer support was withdrawn, his average community participation rate decreased to 1.4 outings per day. Mick's daily community participation rate went to 1.33 outings per day when peer support was re-introduced in the last condition. Mick's community participation rate ranged from 0 to 4 outings a day during the intervention and varied within each condition. In summary, Mick had the highest community participation rate during the baseline conditions and his participation rate continued to decline as the intervention progressed.

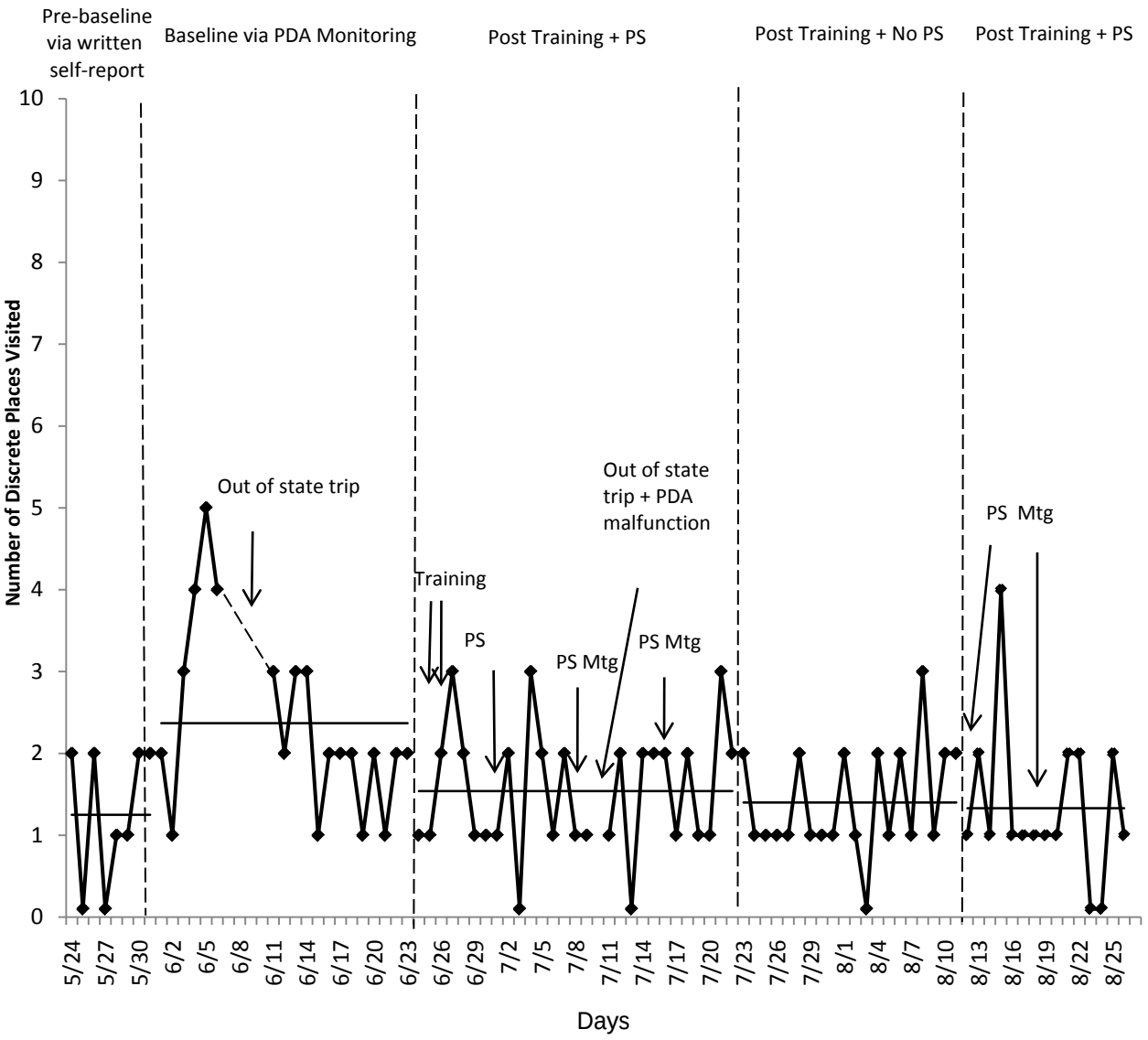


Figure 4. Mick's Community Participation Data

Figure 5 shows a number of discrete places visited in the community by Don who had an average of 1 outing per day during the pre-baseline condition. His community participation rate increased to 1.56 outings per day during the baseline condition. After the training and peer support were implemented, Don's community participation rate increased to 1.62 outings per day.

Don's highest community participation rate occurred during the post training and no peer support condition with an average rate of 2.1 outings per day. This is the phase when he accomplished his goal of enrolling in a Tai-Chi class and started attending the class each week. However, his community participation rate decreased to 1.93 outings per day when peer support was re-introduced in the last condition. Don's community participation rate ranged from 0 to 7 outings a day. Overall, there is a high degree of variability within each condition and a slight increase in community participation was observed.

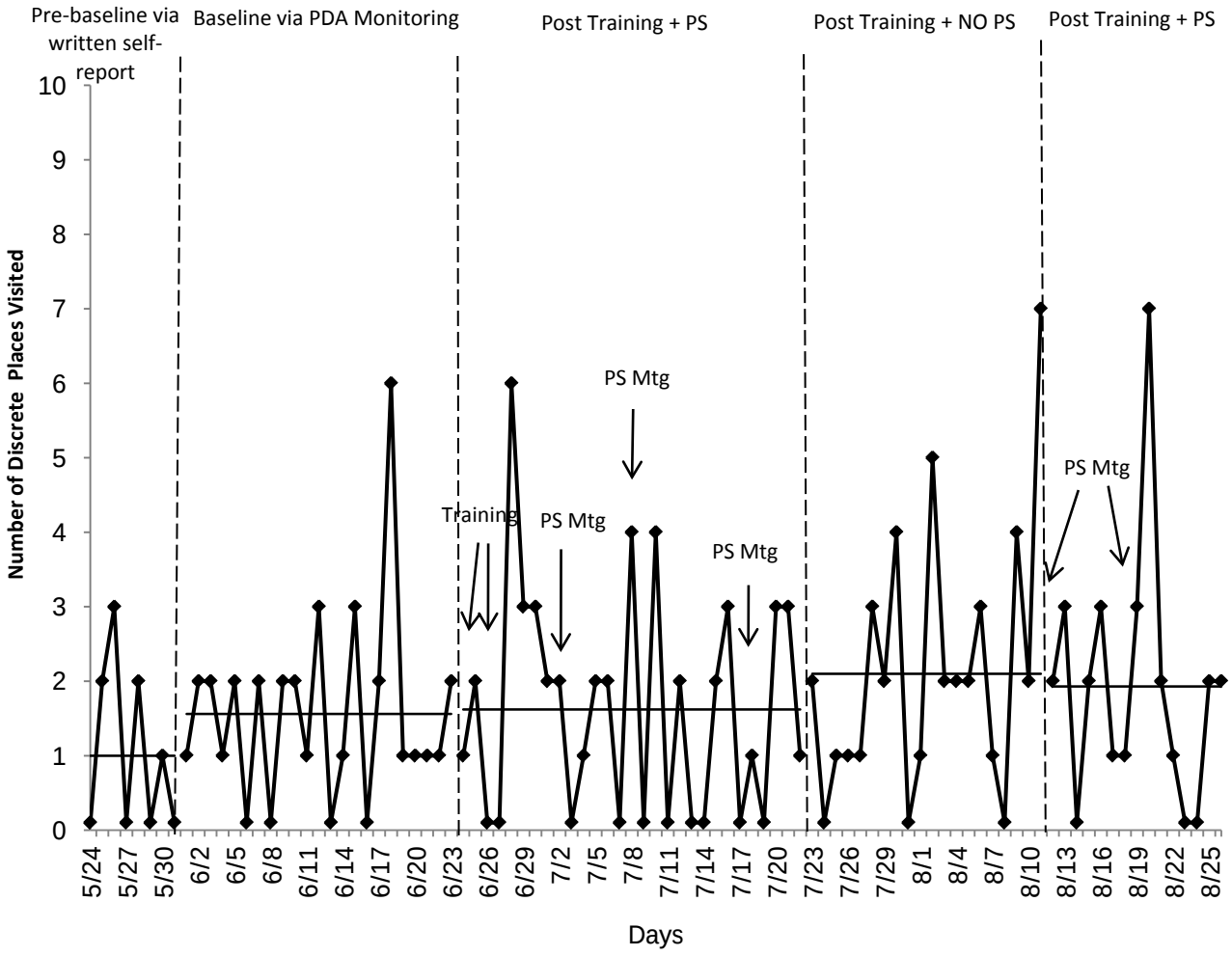


Figure 5. Don's Community Participation Data

Cumulative number of action steps, objectives and goals accomplished. Figure 6 presents a cumulative number of goals, objectives and action steps completed by Mick. Mick's goal was to obtain any type of part-time employment position in his community. After the training, Mick reported completing nine action steps that were related to his goal (i.e., updating his resume, contacting possible employers, etc.). Mick reported accomplishing one objective during the fourth peer support meeting (i.e., to get his wheelchair repaired) but was not able to achieve another objective or goal before the study concluded. According to the follow-up interview conducted 10 weeks after the intervention ended, Mick reported that he had contacted several employers to ask about job openings. He was told he would be placed on waiting lists and contacted when positions became available. Five months later, Mick reported to the researcher that he had participated in two job interviews and was waiting to hear from the employers.

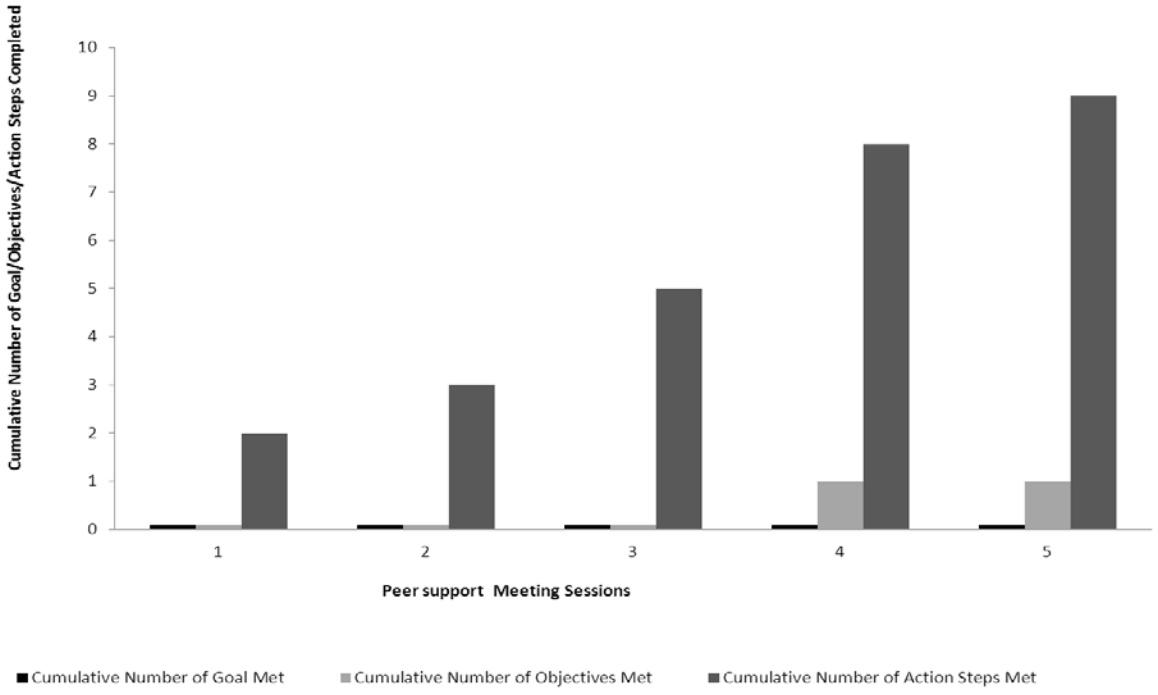


Figure 6. Mike's Progress Toward Goal

Figure 7 depicts a cumulative number of goals, objectives, and action steps completed by Don, whose goal was to enroll in a weekly Tai-Chi class to improve his balance. He completed six actions steps toward his goal (i.e., contacting the senior center regarding classes, reading a book about Tai-Chi) by the end of the study. In the fourth peer support meeting, he reported reaching his goal of enrolling in a weekly Tai-Chi class and then attended a Tai-Chi class every Friday morning with his wife. He accomplished his goal without completing any objectives he set (i.e., finding a Tai-Chi buddy, pursuing a balance test with a physical therapist). Don reported in the 10 week follow-up communication that he continued to go to Tai-Chi class every week and saw positive improvement on his balance.

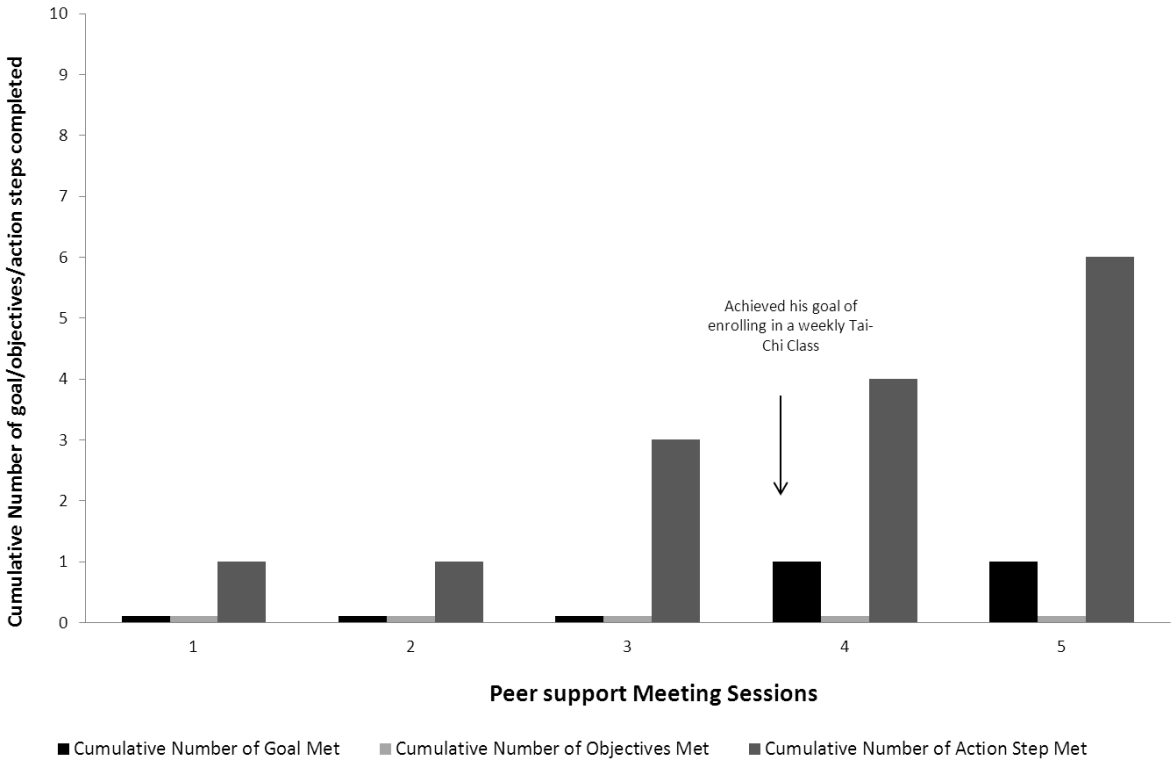


Figure 7. Don's Progress Toward Goal

Social validity. At the end of the study, participants were asked to complete a social validity evaluation regarding the intervention procedures and outcomes, and both expressed satisfaction with them. Don completed the survey himself, but Mick asked the researcher to record his response due to his cerebral palsy. Overall, participants reported positive experiences regarding the intervention. A summary of the responses is presented in Appendix S.

Reliability

Pretest and posttest. Inter-observer agreement for the pre and posttests were calculated for each training chapter and each participant. Secondary observation was conducted by a research staff member who was familiar with the training content. Both observers used a key sheet to grade the tests containing multiple choice, fill-in-the-blank, matching, true or false, and skill application questions. For Mick's pre and posttest scores, the overall agreement rate was 87.5%, or 14 out of 16 questions. For Don, the overall agreement rate was the same, 87.5%, or 14 out of 16 questions. (Final scores were determined after the primary and secondary observers examined both scores and responses where discrepancies were found and discussed until consensus was reached.)

Number of discrete outing per day. Inter-observer agreement for the number of daily outings was calculated by having a second observer compare the number of self-reported outings to numbers and types of permanent products submitted by each participant. First, the researcher wrote down a list of dates when there was at least one outing. (For example, Mick had 19 dates with at least one outing in the community during the 19 days of baseline condition.) Second, the researcher randomly selected dates representing approximately 30% of all dates in each condition for each participant. (For Mick, the researcher randomly picked six dates out of 19 dates from the list.) Third, the researcher placed the permanent products from those six dates into

a separate file for the second observer to review. Finally, the second observer wrote down the types of permanent products submitted (e.g., receipt, photo, church bulletin), and time and location of outings indicated on the permanent products on the reliability check sheet (Appendix T). A reliability assessment was not conducted if there was a missing permanent product. For example, 25 dates were randomly selected for Mick's reliability assessments. However, there were two dates where one or more permanent products were missing; therefore, reliability assessments for those two dates were excluded. Mick's overall reliability score was 100%, or 23 of 23 days. For Don, the overall reliability score was 100%, or 22 of 22 days.

Number of goals, objectives, and action steps completed. Inter-observer agreement for the number of goals, objectives and action steps completed was calculated for each participant by having a second observer listen to the recorded audio files of the peer support sessions. The second observer wrote down the number and details of self-reported goals, objectives and action steps on a scoring sheet (Appendix U) while listening to audio files of each peer support session. For Mick, the agreement rate was 90%, or nine of 10 reported outcomes. For Don, the agreement was 85.71%, six of seven reported outcomes.

Weekly feedback sessions. Two independent observers assessed the treatment integrity of weekly feedback sessions by listening to audio files of randomly selected sessions representing approximately one-third of all sessions across each condition and phase of the study. The observers then completed the reliability assessment form (Appendix V). For Mick, the overall agreement rate was 96.82%, for a total of nine sessions. For Don, the overall agreement rate was 98.57%, for a total of 10 sessions.

Discussion

The results of this study suggest that the *Get Out & About!* training workshop and peer support meeting were not sufficient to increase community participation for participants with mobility-related disabilities. In response to research question one, both participants increased their overall knowledge and skill test scores by an average of 22.5%, indicating that participants were able to acquire knowledge and skills from the *Get Out & About!* training workshop.

Regarding participants' frequency of community participation, Mick did not increase his community participation rate over his baseline level. Don's community participation rate was highest during the post-training and no peer support condition despite our hypothesis that peer support might facilitate increased community participation. Even though noticeable increased community participation was not observed for either participant, Don made significant progress toward reaching his goal of enrolling in weekly Tai-Chi class as a result of the *Get Out & About!* training package. Mick chose a more complex and distal goal (i.e., obtaining part-time employment), which might not have been an attainable goal during the course of a 12-week study. Also the country was in the throes of a severe economic downturn and the unemployment rate was about 9.6% during this time (U.S. Department of Labor, Bureau of Labor Statistics, 2011).

Both participants expressed that the weekly peer support sessions helped them to pursue their goals. It is possible that the *Get Out & About!* training workshop may be necessary to help participants meet their goals, but perhaps not sufficient to get them out into the community more frequently. This may partly be due to participants spending more time in their homes making phone calls, searching on the web and/or reading the newspaper to complete action steps in order to accomplish their stated goals.

While the main study goal was not achieved, we were able to determine that our monitoring device (PDA to self-report community participation) was successful and reliable. Having participants submit the permanent products associated with their outings verified their self-reported community participation activities. Using the PDA to collect data and measure community participation was remarkably successful. In contrast to a similar study by Seekins et al., (2007), participants in this study had steady and high PDA survey completion rates (i.e., Mick = 97. 4%, Don = 99.7%). These results suggest that the high PDA completion rate may have been achieved and maintained by having a contingency contract based on the percentage of on-time PDA survey entries. The lower the completion rate, the smaller the incentive that was paid out at the end of the study. Additionally, PDA performance feedback provided twice a week by the researcher might also have accounted for the high PDA survey completion rate. Both participants produced high verification levels of their self-reported community participation activities by submitting permanent products associated with their outings throughout the study (e.g., Don = 100%, Mick = 85.6%). Initially, the PDA was used as a dependent measure to monitor community participation of study participants. However, the data suggest that in addition to measuring participant's outings, the PDA also may have functioned as a prompt; participants' behavior when the PDA was introduced suggested that they were reactive to PDA prompting as noted by the increases in the baseline condition.

This study has a number of limitations. First, the experimental design employed in this study has possible threats to both internal and external validity. The ABCDC design does not control for participants' history and maturation. It is possible that there were "a group of possible effects of season or of institutional-event schedule" (pg. 7) and "biological or psychological process which systematically vary with the passage of time, independent of specific external

events" (pg. 8) that might have occurred during the intervention periods described by Campbell and Stanley (1963). Another threat to internal validity is instrumentation. Participants were instructed to enter data on the PDA four times a day, seven days a week for almost three months. As participants became accustomed to entering data on the PDA, response fatigue or shifts in reporting method and interpretation of community participation definitions may have occurred. In terms of the external validity, results from the first study have limited generalization, due to a small sample.

Second, there was a delay in observing and counting target behaviors due to the nature of the data collection procedure designed for this study. The researcher collected data from each participant twice weekly (sometimes only once weekly due to a schedule conflict) by visiting their homes and exchanging the PDA. The researcher then took the PDA with recently collected data to the office for data retrieval and analysis. This procedural limitation made it difficult to keep track of real-time behavior change and determine when condition changes should be made.

Third, there might have been some reactivity due to having participants as observers of their own behaviors. However, there have been mixed results on the effects of self-monitoring or self-recording and reactivity. For example, behavior analysis literature (e.g., Critchfield, 1999; Hay, Nelson, & Hay, 1980; Kirby, Fowler, & Baer, 1991) cautions about obtrusiveness of self-monitoring or self-recording measurement procedure and its effect on participants' performance. Alternately, some Ecological Momentary Assessment literature reports little or no evidence of reactive effects (e.g., Hufford & Shiffman, 2002; Stone, Broderick, Schwartz, Shiffman, Litcher-Kelly, & Calvanese, 2003).

Finally, the design and results do not allow to detect the inference of functional relationship between the dependent variables and independent variables. The data showed

considerable variability within and across the conditions. This might be due to unknown extraneous variables and other environmental events (e.g., hot or cold weather) that may have affected the degree of community participation. For example, extreme weather affected Don's stamina which limited his ability to go out by himself for more than a few hours. Mick could not go out by himself when pouring rain or lightning occurred in order to avoid being injured or damaging the electric parts of his power wheelchair.

Even though the study did not show robust functional control, the study has several strengths. First, the current study supported the utility of using a PDA to collect data and measure complex behaviors. Challenges associated with reliance on self-report data such as ensuring report accuracy, were addressed through the collection of permanent products. Also, the procedure of having participants report their community participation activities every three hours, instead of at the end of the day, helped to minimize recall bias.

Second, the study was conducted in participants' natural environments where community participation behaviors typically occur. Data captured during the study yielded a wealth of information. It showed not only instances of community participation, but it also gathered information on types of activity, places of activity, social contexts, duration, and satisfaction across time. In future studies, statistical analysis would be beneficial to analyze and explore which variables predict greater satisfaction and relate to higher rates of community participation.

Finally, both participants gave positive feedback via the social validity survey although their community participation was not greatly increased. Both participants said they would recommend the training to their friends who have similar disabilities. It was also encouraging to learn that one participant (Don) maintained his goal and another participant (Mick) continued to work on his goal attainment at 10 week and six month follow-up points.

Based on the lessons learned from the Study 1, the next study examined the effects of visual and oral feedback on increasing frequency and duration of community participation for individuals with mobility-related disabilities. Study 2 also incorporated use of PDAs to collect data on community participation.

Study 2

This study empirically examined the effects of visual and oral feedback on increasing the frequency and duration of community participation of three individuals with mobility-related disabilities.

Performance feedback technique was incorporated to provide participants with a report on their community participation progress. Performance feedback may be delivered in the form of visual or oral feedback and is an effective strategy to increase the occurrence of desirable behaviors (Alavosius & Sulzer-Azaroff; 1986; Brobst & Ward, 2002; Codding, Feinberg, Dunn, & Pace; 2005; Houten, Hill, and Parsons; 1975). Even though performance feedback usually involves either visual or oral feedback, Trap, Milner-Davis, Joseph, and Cooper (1978) demonstrated the effectiveness of using both visual and oral feedback techniques to increase a percentage of correct cursive letter writing. In a more recent study, Lingo, Jolilvette and Barton-Arwood (2009) used visual and oral feedback to support appropriate social behavior for students with emotional and behavioral problems. In the current study, visual and oral feedback encompassed four objectives and steps: (a) delivery of a community participation progress charts, (b) review of data, (c) discussion of barriers and facilitators to community participation, and (d) discussion of goals and plans.

Method

Participants. As in Study 1, the participants were individuals with physical disabilities who used mobility devices to get around in the community. They were selected from respondents to recruitment flyers distributed by staff members at two local centers for independent living and the vocational rehabilitation services agency in the area.

Inclusion and Exclusion Criteria. These criteria are similar to those used in Study 1. To be included in the study, potential participants had to be: (a) aged 18-65 years, inclusive, (b) using a mobility-device (e.g., cane, walker, wheelchair) to negotiate the community, and (c) able to provide informed consent. Individuals were excluded if they: (a) were unable to operate the Personal Digital Assistant device (PDA), (b) had a full-time job or other social obligations that might prevent participation in study activities, (c) were living in an institution, nursing home or group-home setting, (d) had a self-declared serious health condition (e.g., COPD, emphysema, rheumatoid arthritis), severe secondary conditions (e.g., pressure sores, depression) and/or another disability (e.g., blindness, deafness, memory loss) that would be a potential barrier to completing assigned tasks, (d) were non-English speakers, and (e) had participated in similar research studies or trainings in the past six months.

Participant one, whom we will call “Mark”, was a 52 year-old African-American single male with cerebral palsy and Type II diabetes who primarily used a power wheelchair for mobility. He sometimes used a manual wheelchair when he went out with his personal care attendant (PCA), using the PCA’s vehicle, which was not lift-equipped. He had a bachelor’s degree in physical sciences, was unemployed and lived alone in a studio apartment, contained within a public housing complex. He received help from a PCA who came 20 hours a week. He primarily used his power wheelchair to get around in the community as a mode of transportation or sometimes used public transportation or his PCA’s vehicle. Mark formally served as president

of a local self-advocacy group that worked to remove accessibility barriers in the city. The group is no longer active due to funding difficulties. Mark serves as a consumer representative on the local accessibility transportation committee, which meets every three months.

Participant two, whom we will call “Carmen”, was a 44 year-old divorced white female with cerebral palsy who used a power wheelchair for mobility. Other self-declared health problems and secondary conditions included gastrointestinal problems and anxiety issues. She had been going to counseling therapy once a week for her anxiety for the past four years. Carmen received her master’s degree in counseling psychology but was unemployed and lived at her friend’s house with a help of a home-care professional for more than 40 hours per week. She had a 10-year-old daughter who did not reside with her but whom she met on Saturdays and on special occasions such as holidays, school-related events, and family outings. Carmen typically used para-transit or dial-a-ride van transportation as her primary method of transportation. Para transit is an accessible door-to-door public transportation service for people with disabilities that offers flexible routes and schedules.

Participant three, whom we will call “Lilly”, was a 57 year-old divorced white female with a muscle and bone disorder known as arthrogryposis, which is congenital. She also had asthma and arthritis. Lilly primarily used a power wheelchair; however, she sometimes would use a manual wheelchair or a walker. She lived in a rented house with two cats and the help of PCA who came 40 hours per week. Lilly often used para-transit and city transit to get around in the community. Her father passed away while study recruitment was being conducted and two weeks before the intervention started. Her divorce was also finalized right after the study started. All of the participants were consumers of the local CIL and recipients of several social services such as social security disability benefits, public housing assistance, and food stamps.

Settings and Materials. The study took place in the capital city of a Midwestern state with a population of approximately 124,000. All community participation activities, including data collection, were conducted in the participants' natural environments (i.e., participants' homes or community locations).

Incentives. As in Study 1, incentives were available at the end of the study and the same contingent contract system was used. The monetary reward was $300 if the participant's PDA completion rate was more than 90% throughout the study. If the participant's PDA completion rate was between 70-89%, the participant received half of the available reward ($150). If the participant's PDA completion rate was below 70%, the participant received one-fourth of the available reward ($75). One other monetary gift was a $10 phone card provided to a consumer who did not have long-distance phone service in order to be able to maintain communication with the researcher.

Experimental Design

This study used a case study approach to test the effectiveness of three different intervention packages to increase the frequency and duration of community participation. The first case study used an ABCD design with the three phases being: (a) baseline via written self-report, (b) baseline via PDA monitoring, (c) visual and oral feedback, and (d) visual and oral feedback, and the review of study goals. The second and third case studies employed an ABC design with the two phases being: (a) baseline via written self-report, (b) baseline via PDA self-monitoring, and (c) PDA plus visual and oral feedback.

Independent Variables. This intervention included several independent variables with the intent of stimulating behavior to promote increased community participation. The

independent variables included: visual feedback, oral feedback, review of study goals, and provision of bus passes. Each of these is described in detail below.

Visual feedback. Charts with visual feedback were given to participants during meetings with the researcher as a stimulus to help them see their community participation progress. These charts displayed a line graph showing the daily frequency of community participation. Participants viewed the graph while the researcher gave a verbal summary of the data. An example of this chart is available in Appendix W.

Oral feedback. Oral feedback was delivered to participants immediately after they were given the chart. Oral feedback included the researcher explaining the chart and summarizing the results of their community participation data reported via the PDA since the last meeting. The oral feedback included providing information on: (a) the total number of discrete outings made, (b) the range of the number of community outings (frequency), (c) the number of non-outing days, and (d) the comparison of these data to the previous week's results. Additionally, the researcher also asked participants about barriers and facilitators they encountered to community participation, and facilitated a discussion to help participants make plans and goals for the next week using a guided script (Appendix X).

Review of study goals. The review of study goals involved re-visiting the eligibility criteria and a reminder about the purpose of the study with the intent of decreasing the frequency of consecutive non-outing days. The review of the study goals was only delivered to Mark because he had two five-day consecutive non-outings observed in the treatment condition and was consistently undecided in making goals or plans to engage in community participation activities. Lilly also had more than two five-day consecutive non-outing sequences during the

treatment condition, but Lilly was willing to make plans and goals even though she didn't accomplish all of the outings that she planned.

Bus passes. Bus passes were given to participants after each participant identified transportation as a barrier to community participation during some of the oral feedback sessions. Bus passes were given to participants to: (a) reduce the financial burden of using the bus to go out, (b) help expand community outing options, (c) provide a tool to reach different locations, and d) to serve as a stimulus. Regular bus passes ($11 value) and para-transit bus passes ($25 value) were made available for free, and participants were asked to select the bus passes they were most likely to use. Participants decided when, where, and how often to use their bus pass and could request additional bus passes when they had completed the ones given to them previously.

Dependent Variables. Different participation measures were used to assess behavioral change with the intent of measuring functional control. These dependent variables included: (a) number of discrete places visited per day, (b) duration of daily community outings, (c) proportion of days with two or more consecutive non-outing, and (d) types of locations and activities. Each of these is described in detail below.

Number of discrete places visited per day. As in Study 1, community participation was defined as one discrete event executed: (a) outside of the participants' homes and/or property, and (b) within 50 miles of the participants' homes. It was not considered community participation if the participant traveled out-of-state for a vacation. An additional exclusion criterion was added to the current study. It was not considered community participation if a participant visited the same place more than once a week for an extended period of time. For example, Carmen had been attending counseling appointments once weekly for more than four

years. Similarly, Mark had been visiting a Meals on Wheels congregate site located right next to his apartment complex, Monday through Friday, for a number of years.

Data regarding discrete places visited were logged into PDA devices by participants. The devices emitted a signal that prompted participants to enter data four times daily, at the end of each three-hour period during 12 p.m. - 9 p.m. Following each prompt, participants accessed the PDA and answered a brief six-question survey on their community participation activities in the past three hours.

Duration of daily community outings. These data were collected via self-reports on the PDA device. At each signaled prompt, participants reported on the approximate duration of time spent outside of their homes on their community outings. There were five response options (see Table 2) and participants were asked to choose the duration response that best matched their outing duration.

Proportion of days with two or more consecutive non-outings. The proportion of two or more consecutive non-outing days was calculated by counting these days in each condition and dividing those by the total number of days in each specific condition.

Types of locations and activities. These data were collected via self-reports on the PDA device. At each signaled prompt, participants reported the locations and the type of activities they engaged in the past three hours. Participants could select multiple locations and activities from the list of options (see Table 2) at each survey.

Procedures

Recruitment. Staff members at two different CILs and staff of the state vocational rehabilitation services agency informed their consumers about the study (Appendix Y). Prospective study participants contacted the researchers by phone if they were interested in

enrolling. A consumer who did not have long-distance phone service gave his or her case manager permission to be contacted by the researcher. The researcher then conducted a screening phone survey (Appendix I) to assess initial eligibility of each of the nine prospective participants who expressed interest in the study. Based on the screening interview, four individuals were selected to participate in the study and were notified of their eligibility via surface mail. As in Study 1, those who did not meet the criteria were notified of their non-eligibility via surface mail with the information on the LWWD training workshop available through their local CIL and told they could attend free workshops if they wished. The researcher then scheduled a meeting with each of the eligible persons in their homes to provide details of the study, review the consent form (Appendix Z), and formally enroll them if they were interested. The researcher could not reach one eligible person for two weeks so this individual was dropped from the study. After consent forms were signed, the researcher asked participants to fill out the pre-enrollment survey (Appendix J) to inform the researcher more about their demographic information and obtain pre-baseline levels of their community participation.

Baseline via written self-report. During the baseline condition, participants were asked to recall and write down the names of places they visited in the past three to seven days on a piece of blank paper. If they had not left their homes in the past three to seven days, they were asked to leave the paper blank. The researcher visited participants' homes (or a preferred location, such as a library) once or twice weekly, collected the participants' trip list, and interviewed them with a guided script (Appendix AA) to gather more detailed information on when, what, where, with whom, and how long they participated in the community during the previous week. These interviews were recorded using a digital audio recorder with permission of the participants. The researcher informally asked participants to save permanent products associated with their outings

(e.g., receipts, tickets, brochures or medical appointment cards) from the previous week. The researcher made a copy of all permanent products provided and returned them to participants at the next visit.

Baseline via PDA self-monitoring. After stable baseline data was obtained, participants were asked to carry a Personal Digital Assistant (PDA) to self-monitor their community participation in place of the trip list. The Treo Handspring Visor Pro Personal Digital Assistant (Palm, Inc., Sunnyvale, CA) was used to monitor participants' community participation. As in Study 1, the PDA was pre-programmed to signal four times, every three hours during a 12-hour window. At each prompt, participants accessed their PDAs as soon as they were able and answered a short survey. Before using the PDA, each participant received individualized training on its operation. The same training procedure and materials as in Study 1 were used. Immediately following the PDA training, each participant carried a PDA which had been pre-programmed to signal four times a day (12, 3, 6 and 9 p.m.). Four days into the PDA self-monitoring, Carmen requested that her prompting schedule be changed to 10 a.m., 1 p.m., 4 p.m. and 7 p.m. due to her sleep schedule. The same survey was programmed in the PDA as in Study 1 except for a change in the satisfaction question scales. In this study, the scale was set from 1-7, with 1 being very dissatisfied and scale 7 being very satisfied to allow more response differentiation. The six questions and one reminder page were programmed into the PDA and answered by each participant when prompted. Table 2 presents an overview of the community participation questionnaire and response options for each category.

Visual feedback. Throughout the treatment condition, researchers presented participants with a chart showing their frequency of daily community outings, providing a visual illustration of their daily community participation progress. Participants were asked to display their charts in

a conspicuous place (e.g., refrigerator, bathroom mirror, desk, etc.). Mark posted his chart on a refrigerator in the kitchen. Carmen posted her chart on a wall in her bedroom. Lilly's chart was on the coffee table in her living room.

Table 2. Community Participation Survey Questions and Answering Options (adapted from Seekins, Ipsen, & Arnold 2007).

Frequency	Location	Activity	Social Context	Duration	Satisfaction	Reminder
Did you go out in the past 3 hours?	Where did you go in the past three hours?	What kind of activity (or activities) did you engage in?	Who were you primarily doing this activity with?	How long were you out in the community?	On a scale of 1-7, how would you rate satisfaction with this activity?	Make sure to keep your permanent products associated with your outings!
Yes No	Entertainment facility Grocery/Drug Store Gym or exercise facility Health care facility Home Office building Park/forest/lake Public sidewalk Religious facility Restaurant/café/bar Retail store School Someone else's home Other	Education Employment Household chores Leisure Social Self-care Resting Transportation Other	Alone Business Person Family Friends Significant other Mixed group Peers or coworkers Pet(s) Professionals Significant other Strangers Other	Less than 30 min. 30 min. to 1 hour 1 hour to 2 hours 2 hours to 3 hours N/A (didn't go out)	1 = Very dissatisfied 2 = Moderately dissatisfied 3 = Somewhat dissatisfied 4 = Neither dissatisfied or satisfied 5 = Somewhat satisfied 6 = Moderately satisfied 7 = Very satisfied	Yes No

Oral feedback. After giving each participant a chart, the researcher discussed the weekly updated charts with participants at each meeting. The researcher described the chart data and provided a summary of participants' community participation activities. The summary informed participants about: (a) the total number of discrete outings made, (b) the range of the number of community outings (frequency), (c) the number of consecutive non-outing days, and (d) the comparison of those numbers to the previous week's results. The researcher also asked some

guiding questions to learn about barriers and facilitators of community participation that participants experienced during the previous week. The researcher then discussed participants' goals and plans for the upcoming week. The researcher used a script for consistency of the independent variable and recorded conversations using a digital audio recorder. These meetings typically lasted between 15-30 minutes.

Review of the study goals. One participant (Mark) received a review of the original study goals from the researcher after more than two five-days consecutive non-outing were observed in the treatment conditions and he showed little or no interest in making goals or plans for the upcoming week. The review of study goals included re-visiting the eligibility criteria and a reminder about the study purpose, with an intent to decrease the frequency of consecutive non-outing days.

Bus passes. Bus passes were given to participants after each had stated that transportation was a barrier to their community participation. Participants could determine when, where, and how often to use those bus passes and could request another set of bus passes when they finished using all ten passes. Mark received regular bus passes during the first day of the second treatment condition. Carmen received her first set of bus passes seven days into the treatment condition and Lilly received hers after two weeks into the treatment condition. Carmen requested an additional set of bus tickets as often using previously given tickets. Carmen and Lilly both preferred the para-transit bus passes, dial-a-ride transportation that provide riders door-to-door service.

Data retrieval. The researcher visited each participant's home twice weekly (except when the participant/researcher was unavailable) to download data from the PDA to a laptop computer. During these visits, the researcher provided feedback to participants regarding their PDA

completion performance and asked questions regarding outing purposes and content using structured scripts (Appendix N).

As in Study 1, these data were entered into a spreadsheet and analyzed to gain an understanding of participants' community participation activities. At the each data collection meeting, the researcher reviewed this spreadsheet to ensure there were no missed entries. If there was a missed entry, the researcher asked the participant to recall what they were doing at that time, and completed the missed spreadsheet column. If participants did not recall what they were doing at that time, the researcher left the column blank.

Verification of self-reports. As in Study 1, participants were asked to save any permanent products associated with their outings (e.g., sales receipts, ticket stubs, medical appointment cards, brochures, etc.). The researcher collected these products at each data collection meeting and compared them with participants' self-reported data for verification.

Follow-up visits. The researcher visited participants' homes to collect follow-up data and to conduct a brief interview four weeks after the formal data collection ended. The researcher asked participants to recall if they had gone out to the community in the past week and inquired about the context of their community participation activities (e.g., when, where, what, how long, with whom, and satisfaction level). The researcher also asked several guiding questions (Appendix AB) to gather qualitative information about barriers and facilitators of community participation as well as any personal and environmental changes (e.g., increased bus fare, PCA schedule, health conditions, construction in the neighborhood) that occurred in the past four weeks.

Social validity survey. As in Study 1, each participant was asked to independently complete a social validity survey upon completion of the study (Appendix AC). Yes/No

questions and a 5-point Likert-type scale (ranging from 1 = very dissatisfied to 5 = very satisfied) were used for questions concerning the PDA data collection procedures and overall experiences in the study.

Reliability. Reliability assessments were conducted to check the fidelity of independent variable implementation. Independent observers included two undergraduate students and the researcher. As in Study 1, all independent observers were trained by the researcher before performing reliability checks and received extensive instruction and feedback on reliability performance procedure and how to complete the scoring sheets (Appendix AD). Inter-observer agreement was calculated by dividing the number of agreements by the total number of agreements plus disagreements and multiplying by 100 for each participant.

Results

PDA entry completion rate. For Mark, 18 days of baseline data and eight days of follow-up data were collected via retrospective self-reports. A total of 257 data entries were completed on the PDA out of 260 possible entries available across 66 days during two different intervention phases. Mark missed three entries which left him with a 98.8% PDA completion rate. For Carmen, 35 days of baseline data eight days of follow-up data were collected via retrospective self-reports. A total of 198 data entries were made on the PDA out of 196 possible entries available across 50 days of observation period, with a 98.9% completion rate. For Lilly, 45 days of baseline data and six days of follow-up data were collected via retrospective self-reports. A total of 151 data entries were made on the PDA out of 152 possible entries available across 39 days of observation period, with a 99.3% completion rate.

Number of discrete places visited per day. Figure 8 presents the number of discrete places visited in the community by Mark. Mark had an average of 0.67 outings per day during

the baseline via written self-report condition, and 0.96 outings per day during the baseline via PDA self-monitoring condition. His daily community participation rate decreased to 0.18 outings per day during the first intervention condition which included a visual and oral feedback. However, after implementing a review of study goals and adding the incentive of bus passes, Mark's daily community participation rate increased and averaged 0.91 outings per day. During the four-week follow-up condition, his community participation rate decreased to an average 0.43 outings per day. Overall, Mark's community participation outings ranged from 0 to 5 outings a day.

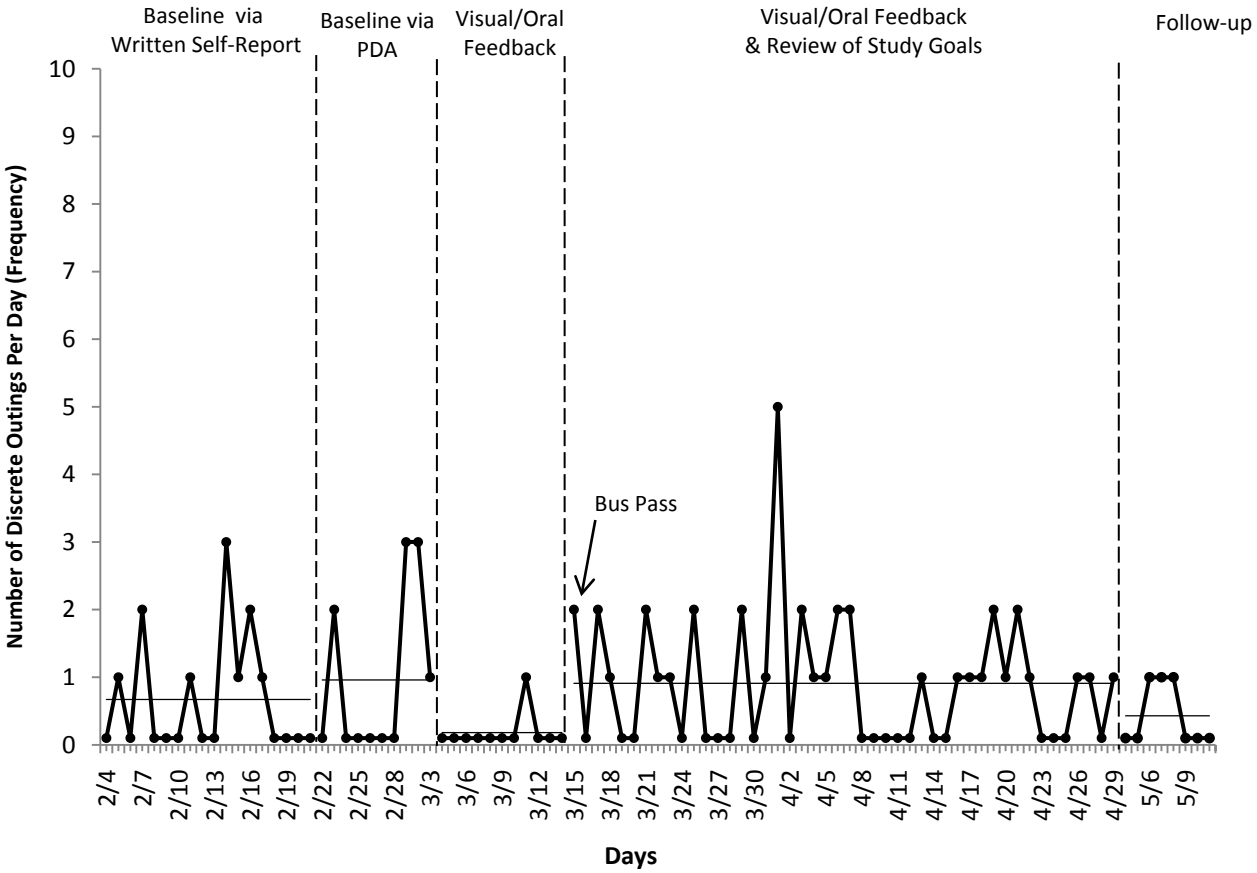


Figure 8. Frequency of Mark's Daily Community Participation

Figure 9 shows the number of discrete places visited in the community by Carmen. Carmen had an average of 1.41 outings per day during the baseline via written self-report condition, and 2.57 outings per day during the baseline via PDA self-monitoring. Her community participation rate increased to 1.66 outings per day during the visual and oral feedback and bus pass condition. Carmen's community participation rate decreased to 1.36 outings per day during the four-week follow-up condition. Carmen's community participation ranged from 0 to 4 outings a day.

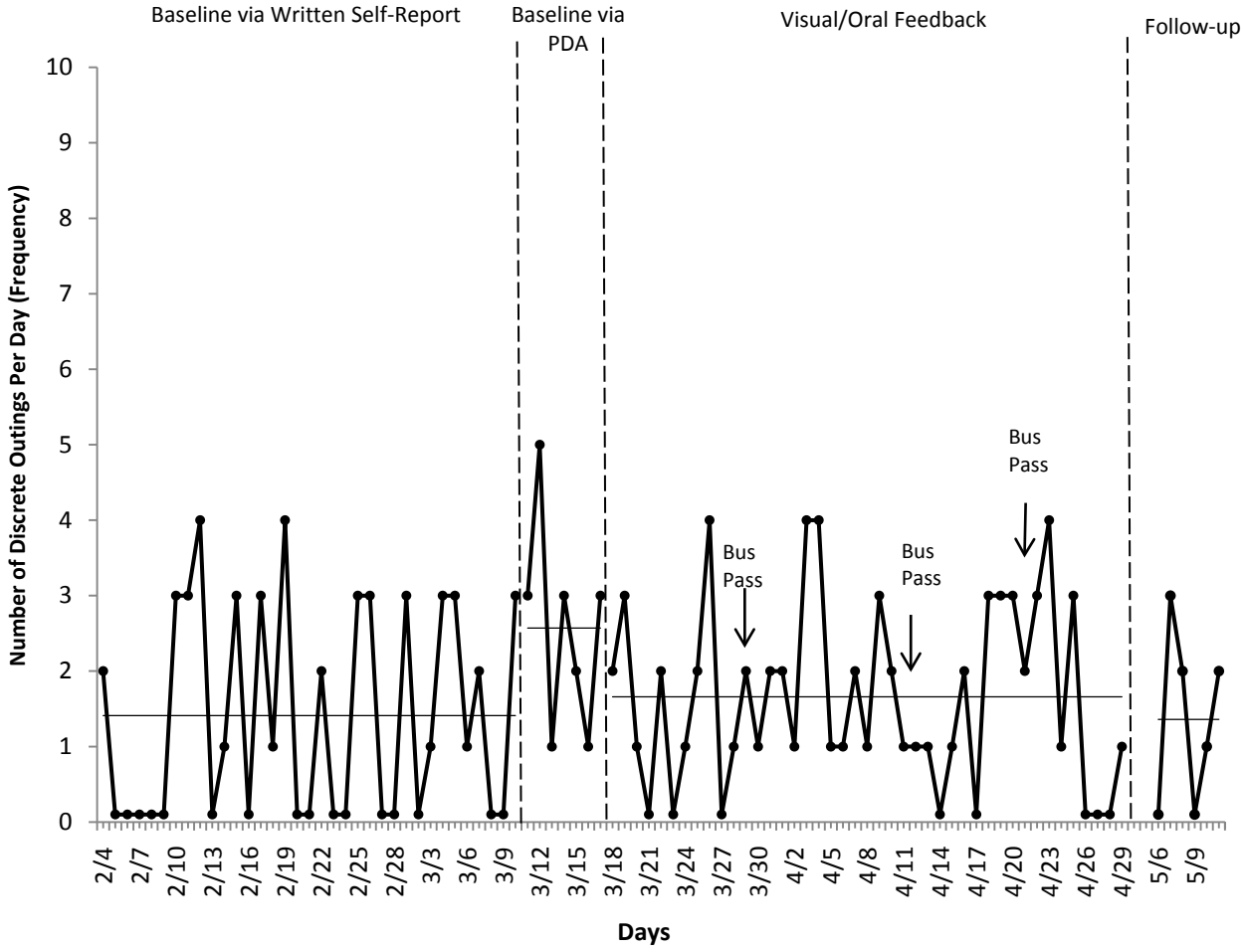


Figure 9. Frequency of Carmen's Daily Community Participation.

Figure 10 depicts the number of discrete places visited in the community by Lilly who had an average of 0.34 outings per day during the baseline via written self-report condition, and 0.47 outings per day during the baseline via PDA self-monitoring condition. Her community participation increased to 0.78 outings per day during the visual and oral feedback and bus pass condition. Lilly's community participation rate decreased to 0.4 outings per day during the follow-up condition. Lilly could not remember her community participation activities for the first two days of follow-up condition due to her limitations on recall. Lilly's community participation rate ranged from 0 to 5 outings a day.

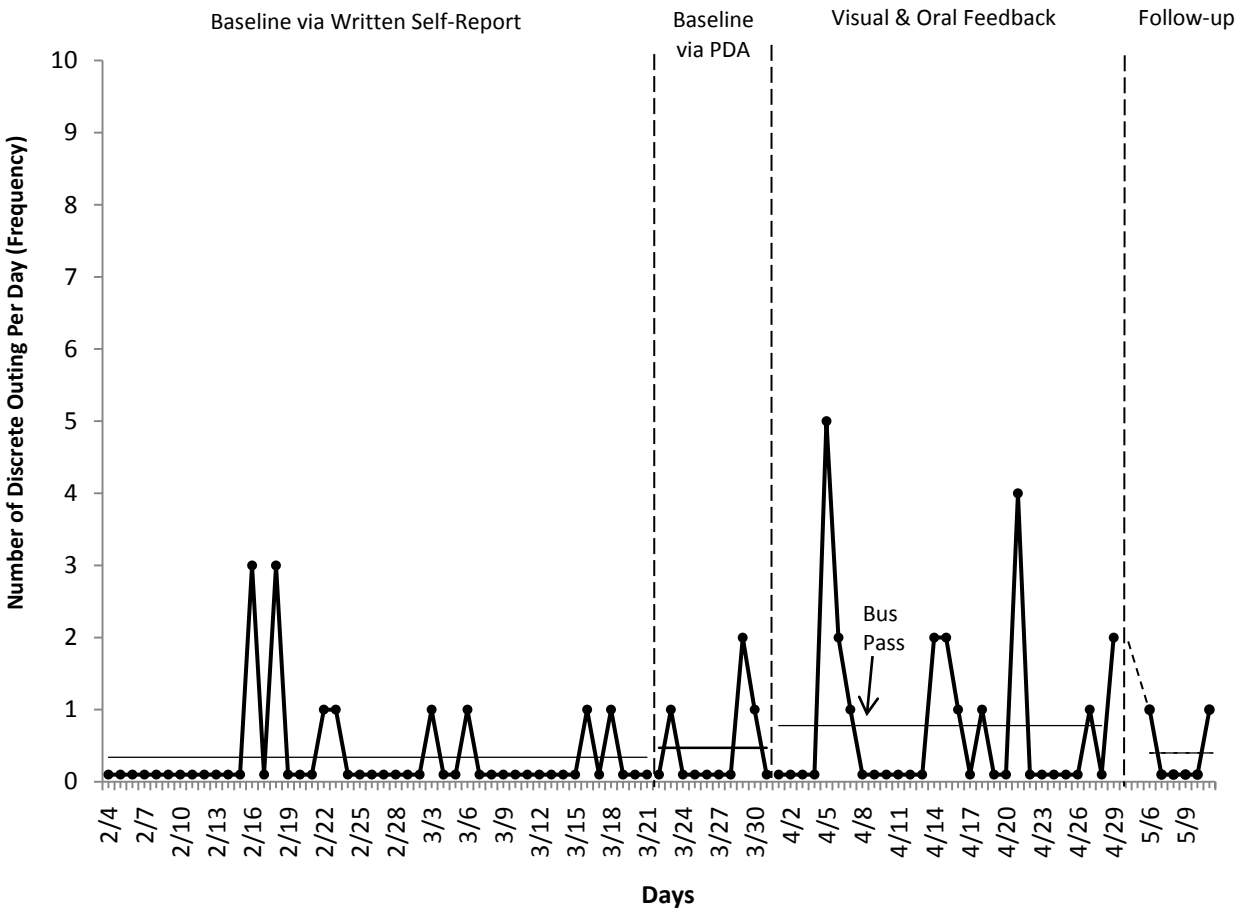


Figure 10. Frequency of Lilly's Daily Community Participation.

Duration of daily community outings. Figure 11 presents a graph of duration (in hours) of daily community outings by Mark. During the baseline condition via written self-report, Mark had a daily average of 0.63 hours spent outside of his house in the community, and 1.05 hours during the baseline via PDA self-monitoring condition. During the first intervention condition, his average duration increased to 0.54 hours a day. During the second intervention condition which included visual and oral feedback, and review of the study goal, his duration almost tripled from the baseline conditions to 1.83 hours a day. However, his average daily duration decreased to 0.96 hours during the first follow-up condition. Mark's daily duration in the community ranged from 0 to 7.5 hours.

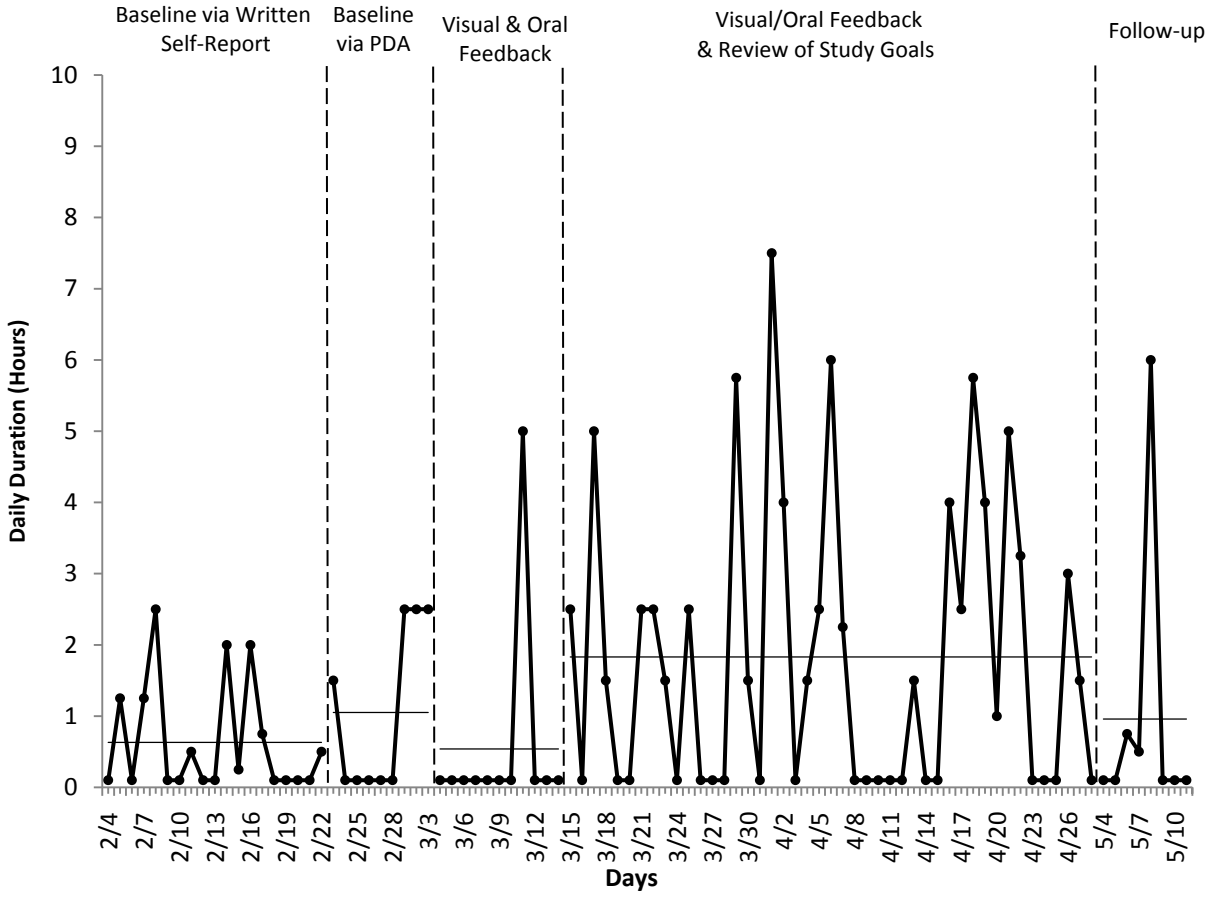


Figure 11. Duration of Mark's Daily Community Participation.

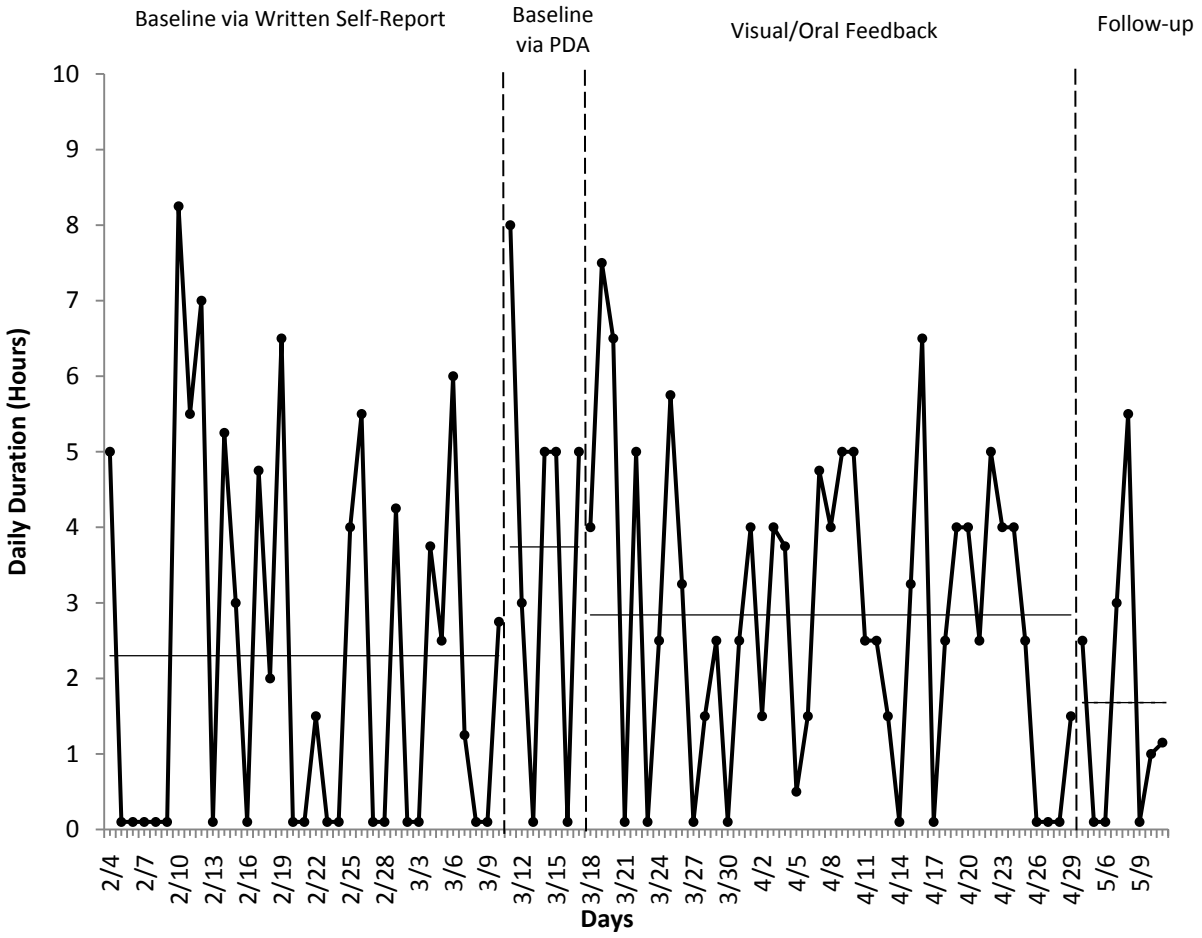


Figure 12. Duration of Carmen's Daily Community Participation.

Figure 12 shows a graph of duration of daily community outings by Carmen. During the baseline condition, Carmen had a daily average of 2.3 hours spent outside of her house and in the community, and 3.74 hours during the baseline via PDA self-monitoring condition. During the intervention condition which included visual and oral feedback and three bus passes, her average duration increased to 2.84 hours a day. Carmen's daily average duration decreased to 1.68 hours during the follow-up condition and was the lowest average of duration among all three different conditions. Carmen's daily duration in the community ranged from 0 to 8 hours.

Figure 13 presents a graph of duration of daily community outings by Lilly. During the baseline condition, Lilly had a daily average of 0.46 hours spent outside of her house and in the community, and 1.97 hours during the baseline via PDA self-monitoring condition. During the intervention condition, her average increased and almost tripled to 1.42 hours a day. Lilly's daily average duration decreased to 1.06 hours during the first follow-up condition, still more than double the baseline condition. Lilly's daily duration in the community ranged from 0 to 8.5 hours.

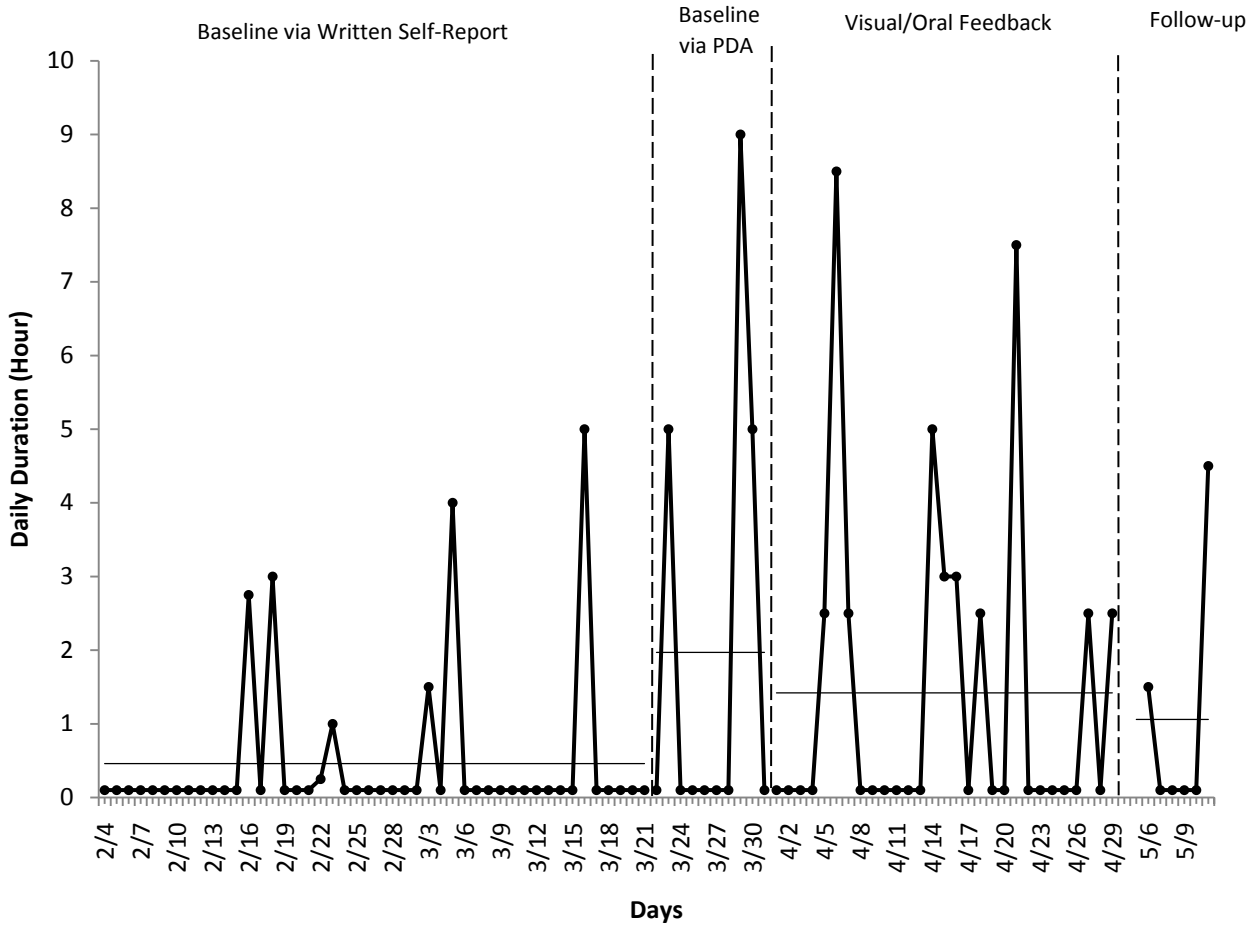


Figure 13. Duration of Lilly's Daily Community Participation

Cumulative duration of hours spent in the community. The next three graphs display the cumulative duration of hours participants spent in the community with trend lines.

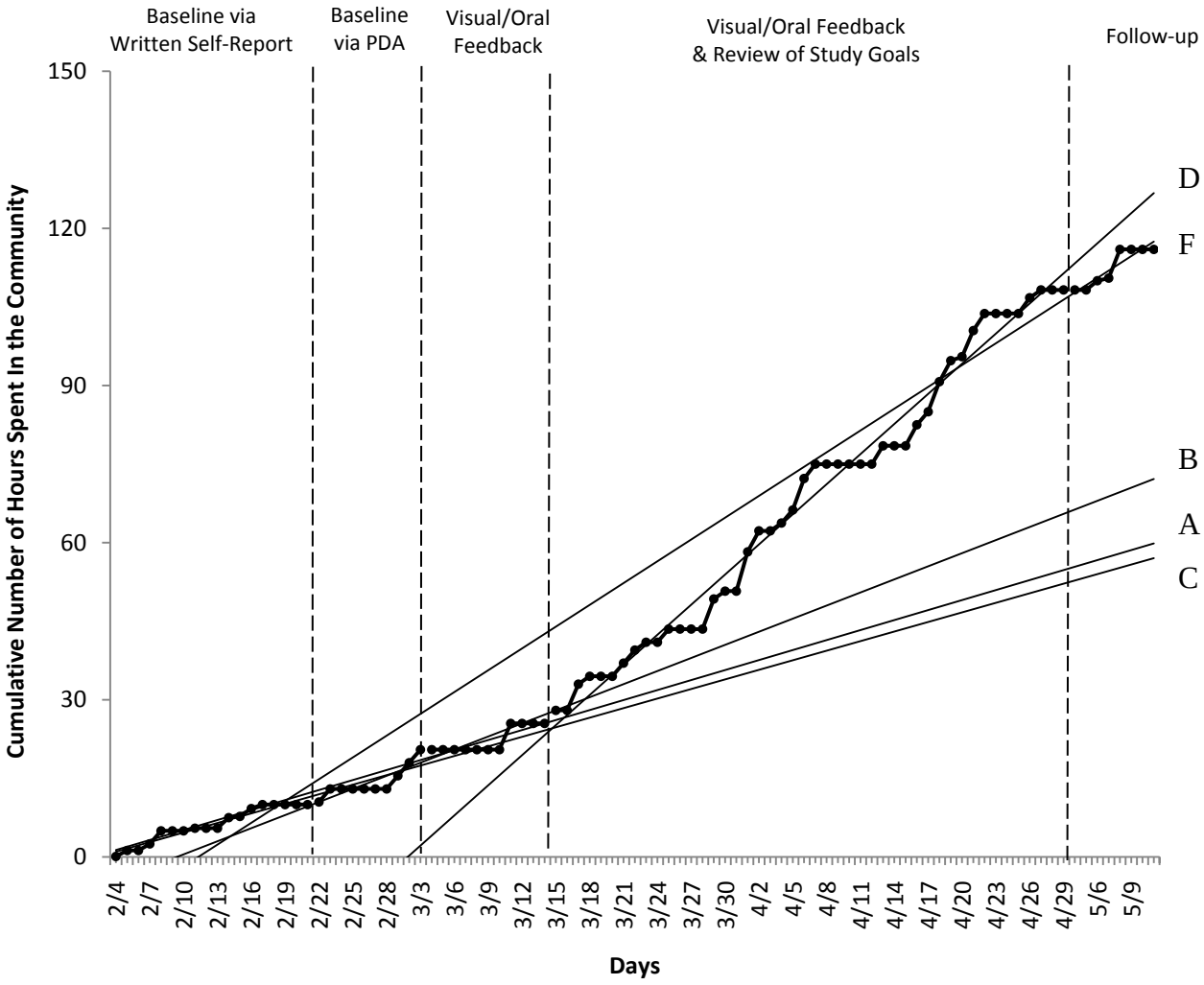


Figure 14. Mark's Cumulative Number of Hours Spent in the Community.

Figure 14 shows Mark's cumulative number of hours spent in the community. The line with the letter A displays Mark's trend line during the baseline via written self-report condition; B is baseline via PDA self-monitoring; C is visual and oral feedback; D is visual and oral

feedback and review of study goals; and E is follow-up condition. The direction of lines indicates that his community participation duration trend changed slightly when the PDA was introduced (B). The direction changed significantly steeper after a review of the study goals were reviewed (D). His trendline remained steep during the follow-up session (E), suggesting continued maintenance of the behavior.

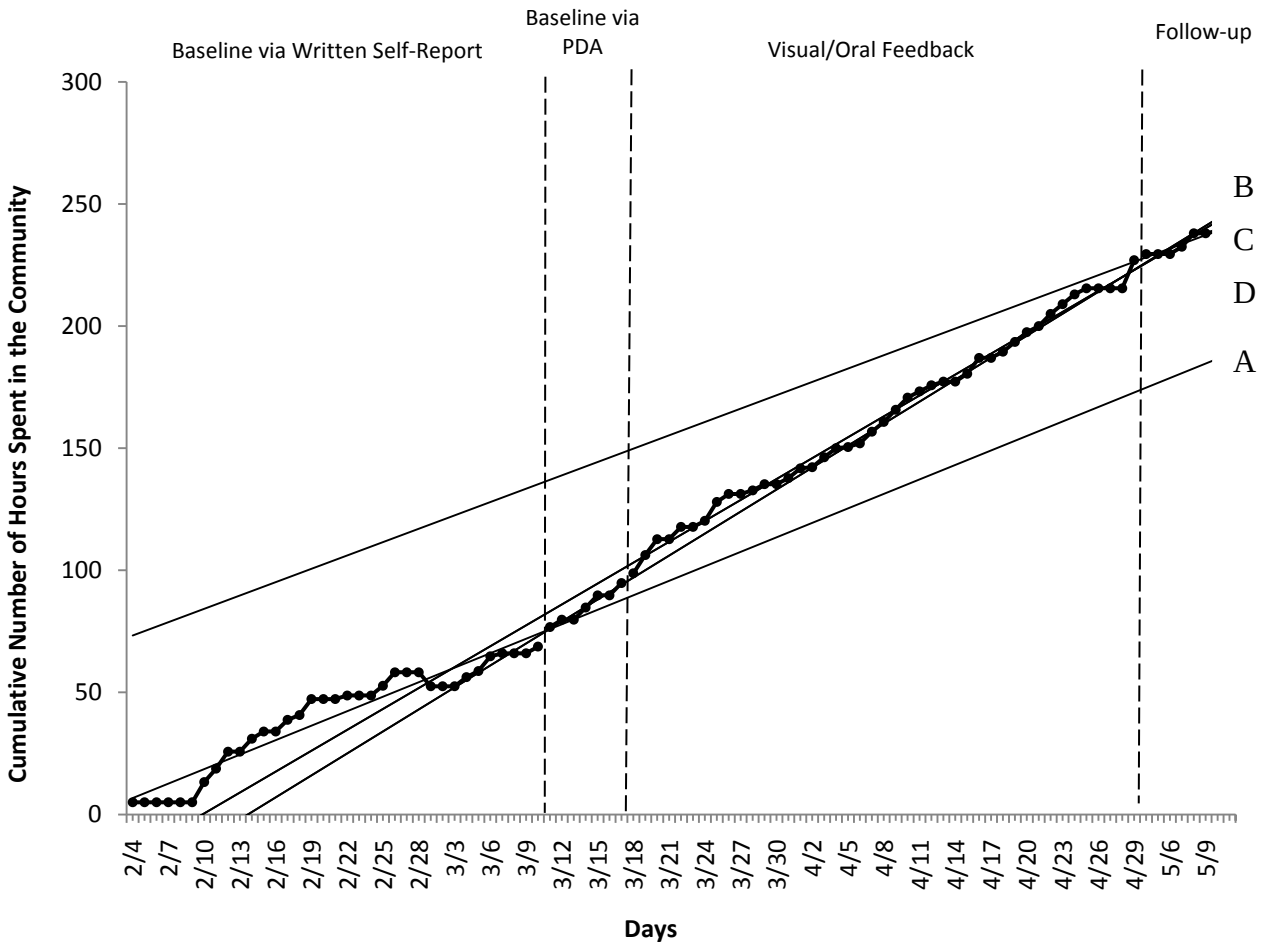


Figure 15. Carmen's Cumulative Number of Hours Spent in the Community.

Figure 15 depicts Carmen's cumulative number of hours spent in the community with trend lines. The scale on the Y axis is different for Carmen. The line with a letter A displays Carmen's trend line during the baseline via written-self-report condition; B is baseline via PDA self-monitoring; C is visual and oral feedback condition; and D is follow-up condition. Carmen consistently increased the duration of hours spent in the community and had the highest total hours spent in the community among all three participants. The chart shows that her trend increased between the first baseline condition (A) and the second baseline condition with the PDA self-monitoring (B). Even though Carmen slightly decreased her duration in the community during the oral and visual feedback condition (C) and follow-up condition (D), the shape of this line is slightly higher than the baseline condition (A).

Figure 16 presents Lilly's cumulative number of hours spent in the community. The line with a letter A displays Carmen's trend line during the baseline via written-self-report condition; B is baseline via PDA self-monitoring condition; C is visual and oral feedback condition; and D is follow-up condition. Though she had frequent consecutive non-outings (ranging from two days to 12 days) throughout the study, the trend lines are steeper during the baseline via PDA self-monitoring (B), visual and oral feedback (C) and follow-up condition (D) than the baseline conditions (A). These lines suggest that she spent longer hours in the community during the intervention condition. Lilly had the least total hours spent in the community among all three participants.

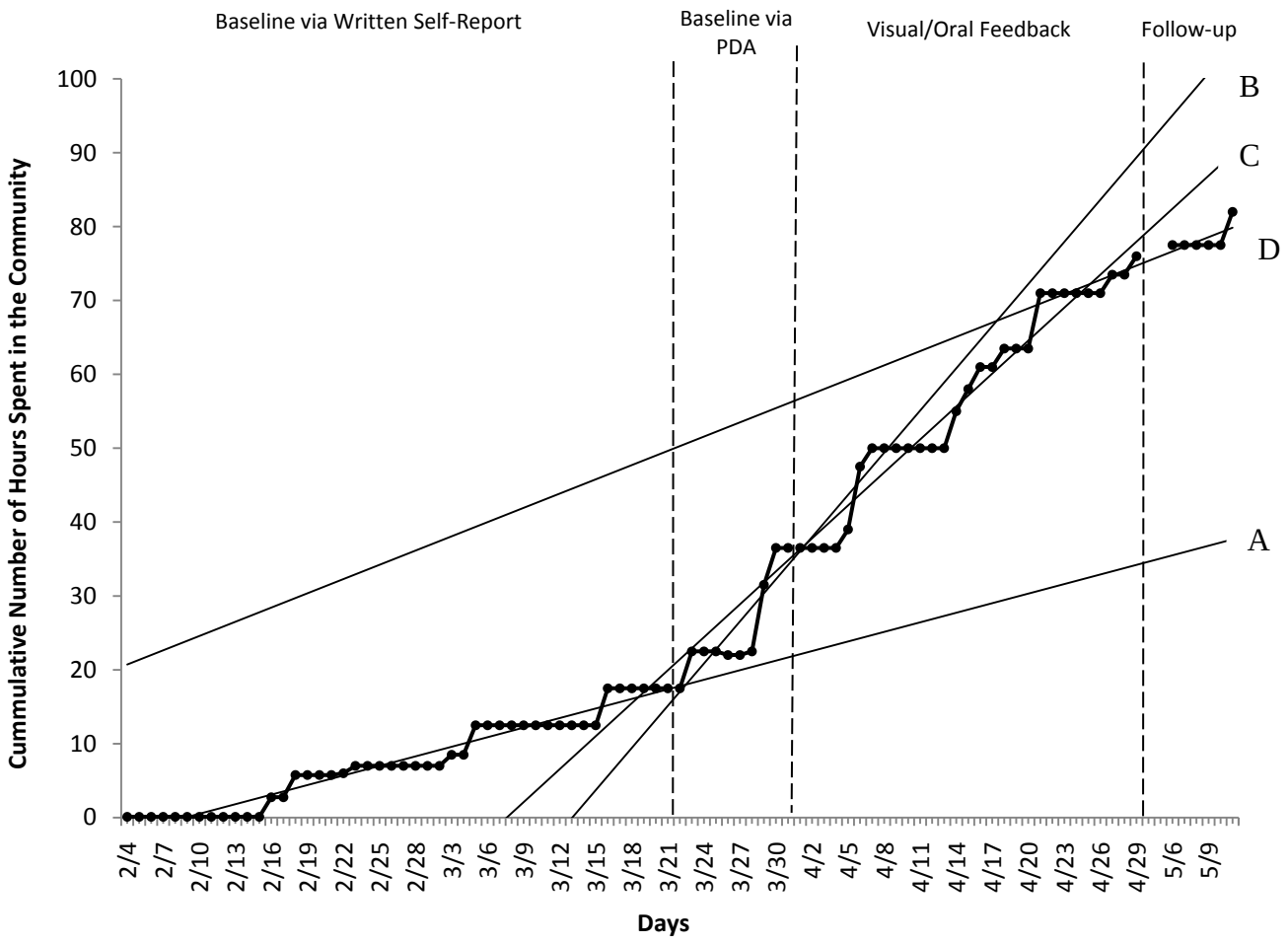


Figure 16. Lilly's Cumulative Number of Hours Spent in the Community.

Proportion of days with two or more days of consecutive non-outings. The next three graphs display data on proportion of days with two or more days of consecutive non-outings.

Figure 17 presents a bar graph containing Mark's proportion of days with two or more consecutive non-outings. Mark's consecutive non-outings ranged from two to seven days. During 18 days of the baseline condition via written self-report, and 10 days of the baseline via PDA self-monitoring, Mark had 50% of his days where there were two or more consecutive non-

outings. The number increased to 90% during the first intervention condition. However, the proportion of his consecutive day non-outings decreased to 32.6% when a review of study goals was implemented. During the four-week follow-up condition, the number of consecutive non-outings increased to 62.5%.

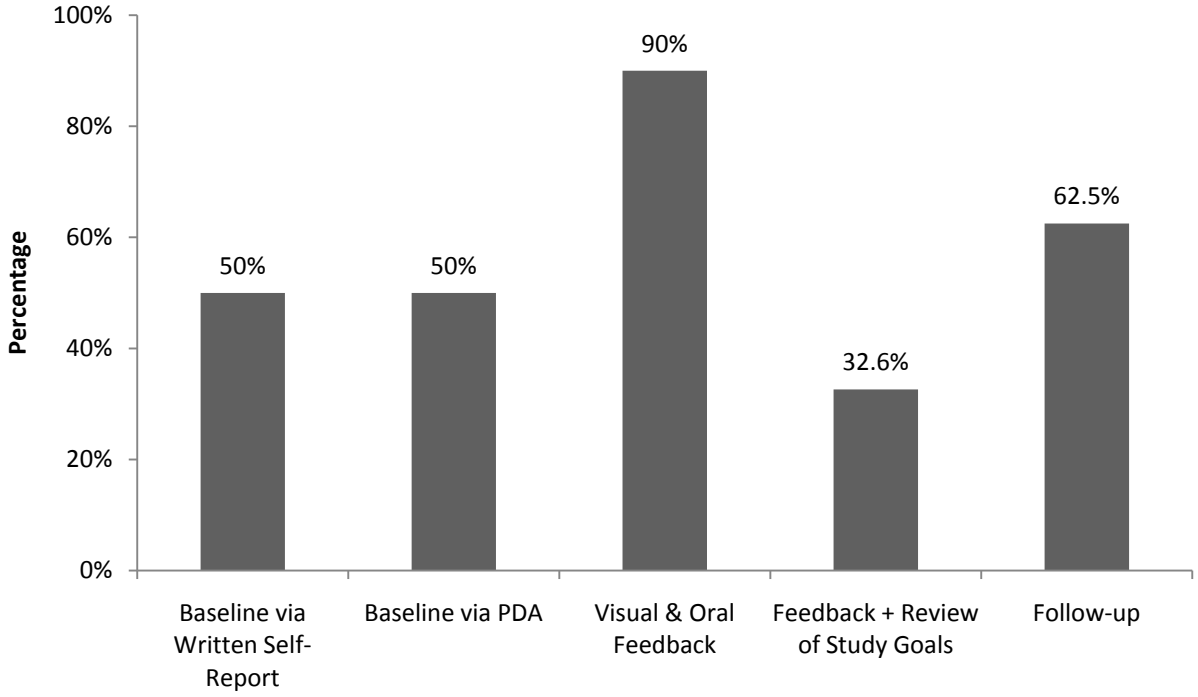


Figure 17. Mark's Proportion of Days with Two or More Consecutive Non-outings.

Figure 18 presents Carmen's progress on consecutive non-outings. Carmen's consecutive non-outings ranged from two days to five days. During 42 days of baseline condition, Carmen had 31% of days where she had two or more consecutive non-outings. During the 7 days of the baseline via PDA self-monitoring condition, the number decreased to 0%, indicating she was out in the community at least every other day most of the time. During the visual and oral feedback condition, the number was 0.07% and Carmen only had one instance of three consecutive non-

outing days. During the four-week follow-up condition, the number decreased to 0% again, suggesting continued maintenance of the behavior.

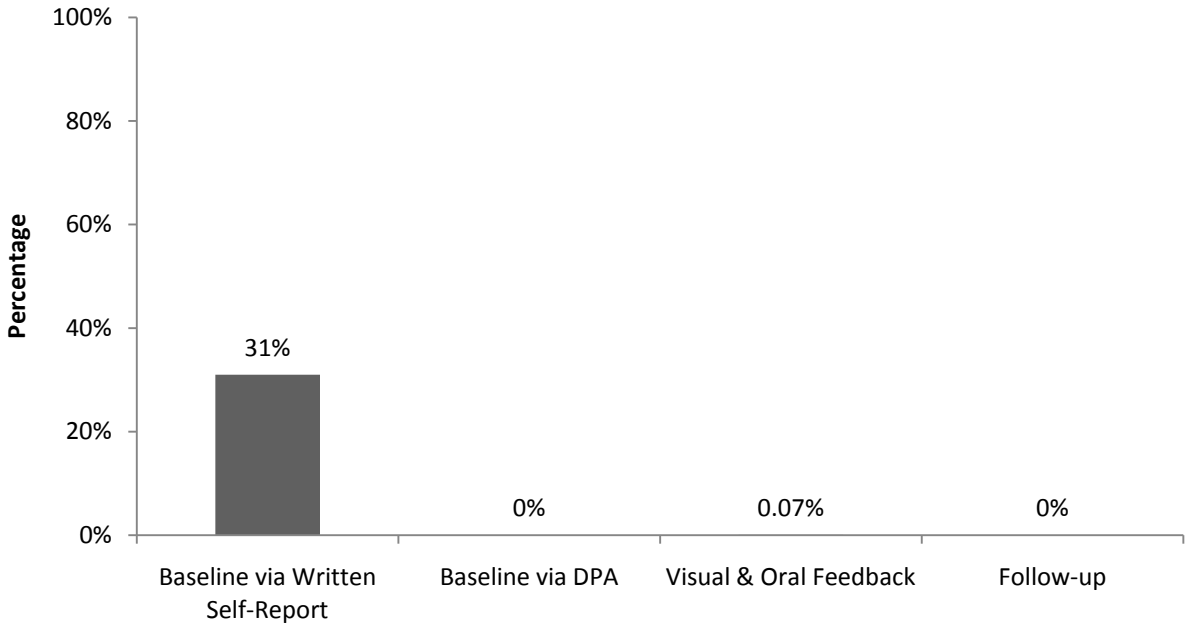


Figure 18. Carmen's Proportion of Days with Two or More Consecutive Non-outings.

Figure 19 presents Lilly's progress on consecutive non-outings. Lilly's consecutive non-outings ranged from two days to 12 days. During 46 days of the baseline condition via written self-report, Lilly had 78.2% of days where she had two or more consecutive non-outings. The number was the lowest at 50% during the baseline via PDA self-monitoring condition. During the intervention condition, she had 58.6% of days with two or more consecutive non-outings. Lilly's range of consecutive non-outings also changed from two to six days. However, the number increased to 66% during the four-week follow-up condition.

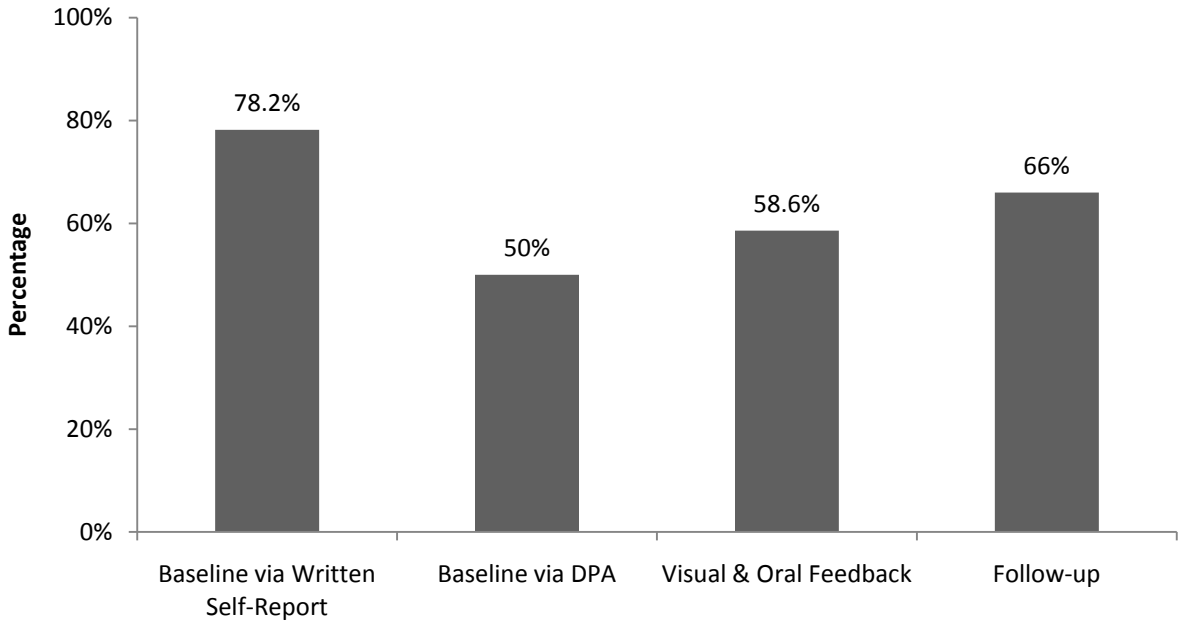


Figure 19. Lilly's Proportion of Days with Two or More Consecutive Non-outings.

Types of Locations. The next three graphs show the type of locations visited by each participant during the intervention conditions. Survey results are reported based on the total number of participants' responses to each question.

Figure 20 presents the type of locations visited by Mark. During 66 days of the PDA reporting period, Mark spent the majority of time at his home (85.2% of observations, n=219). When he was out in the community, he went to a retail store (9%, n=23), restaurant/cafe/bar (4.6%, n=12), entertainment facility (3%, n=7) and office building (2.5%, n=10). Locations reported fewer than 1% of the total observation included gym/exercise facility, hospital/health care provider, park/forest/lake, public sidewalk, religious facility, school and someone else's home.

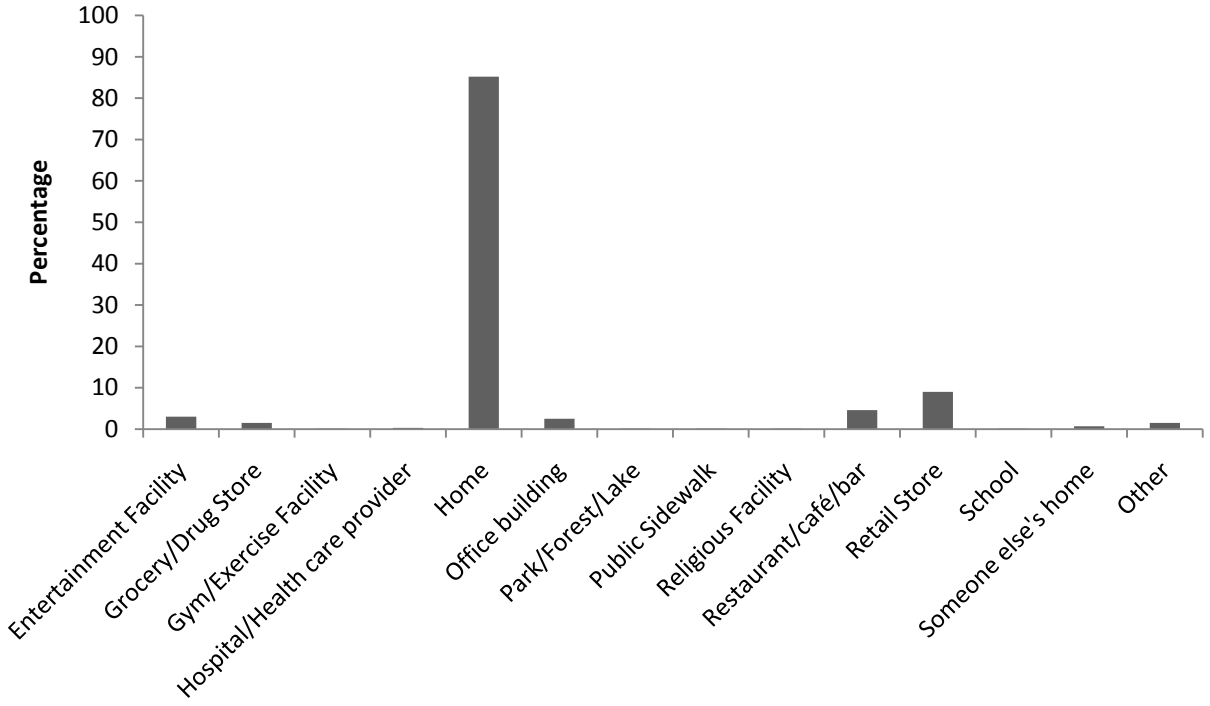


*Figure 20.*Typesof Locations Visited by Mark.

Figure 21 presents the type of locations visited by Carmen. During 50 days of the PDA reporting period, Carmen also spent the majority of time at her home (89.3% of observations, n=177). When she was out in the community, she often went to office buildings (23%, n=45), someone else's home (12.6%, n=26), park/forest/lake (7%, n=14), retail stores (2 %, n=10) and other (1.6%, n=3). She was rarely at a hospitals/health care providers (0.3%, n=1) and grocery/drug stores (0.5%, n=1) and never went to an entertainment facility, gym/exercise facility, religious facility, restaurant/café/bar and school.

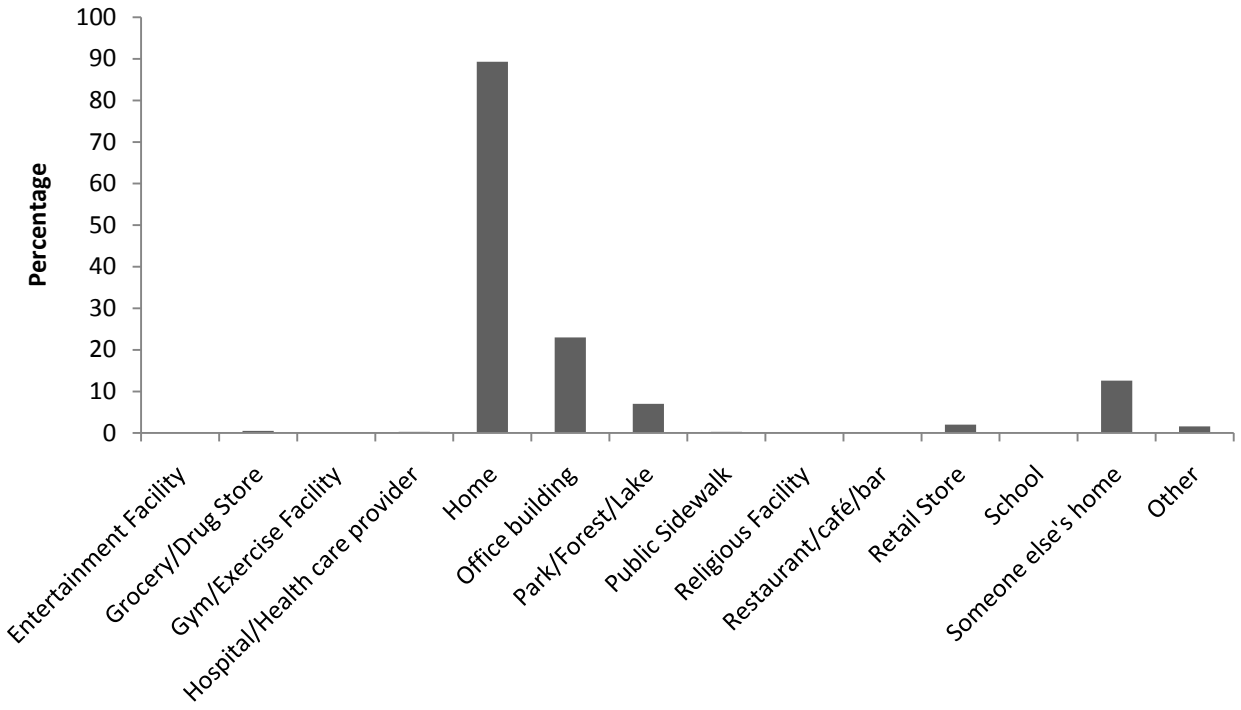


*Figure 21.*Typesof Locations Visited by Carmen.

Figure 22 presents the types of locations visited by Lilly. During the 39 days of PDA reporting, Lilly spent the majority of time at her house (93.3% of observations, n=144). When she was out in the community, she was often at a restaurant/café/bar (15.1%, n=10), health care provider facilities and retail stores (8.6%, n=13) and other (8%, n=12). She didn't go to the places such as entertainment facility, gym/exercise facility, public sidewalk, park/forest/lake, religious facility, restaurant/café/bar, school and someone else's home.

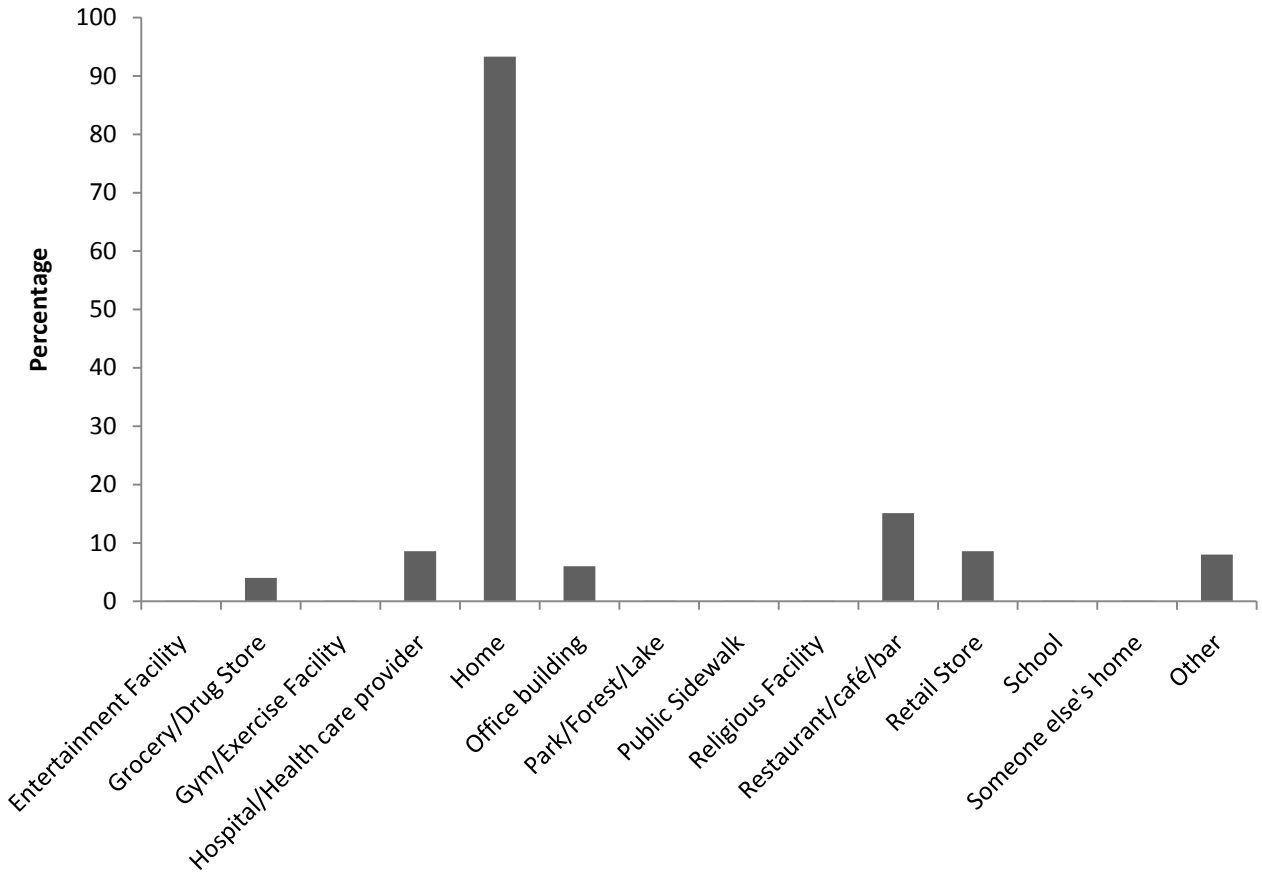


Figure 22. Types of Locations Visited by Lilly.

Types of Activities. The next three graphs present the type of activities engaged in by each participant. Survey results are reported for the total number of responses to each question. Figure 23 shows the type of activities engaged in by Mark. The top five activities that Mark engaged in were: leisure and self-care (58%, n=149), social (44.7%, n=115), resting (25.2%, n=65) and household/chores (25%, n=64). He did not participate in education, employment, service/volunteering and spiritual activities.

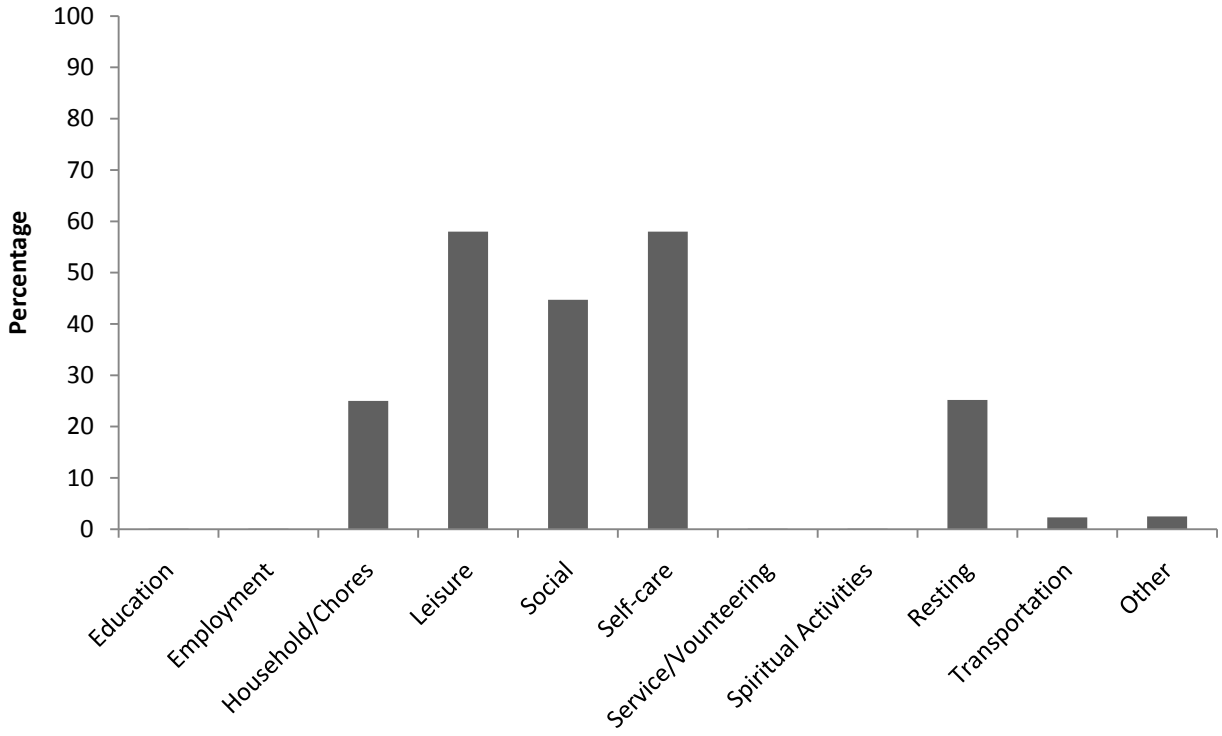


Figure 23. Types of Activities Engaged by Mark.

Figure 24 shows the type of activities engaged in by Carmen. The top five activities Carmen engaged were in: leisure (72.7%, n=144), self-care (56.5%, n=112), resting (22.2%, n=44), household and chores (12.1%, n=24) and social (11.6%, n=23). She did not participate in education, employment, service/volunteering activities and spiritual activities.

Figure 25 shows the type of activities engaged in by Lilly. The top five activities Lilly engaged in were: self-care (90.1%, n=136), household/chores (82.1%, n=124), leisure (81.4%, n=123), social (77.4%, n=117) and resting (77.4%, n=112). She sometimes engaged in transportation (10%, n=15), other (22%, n=33) and educational (1.98%, n=3) activities, but never participated in employment, service/volunteering and spirituality activities.

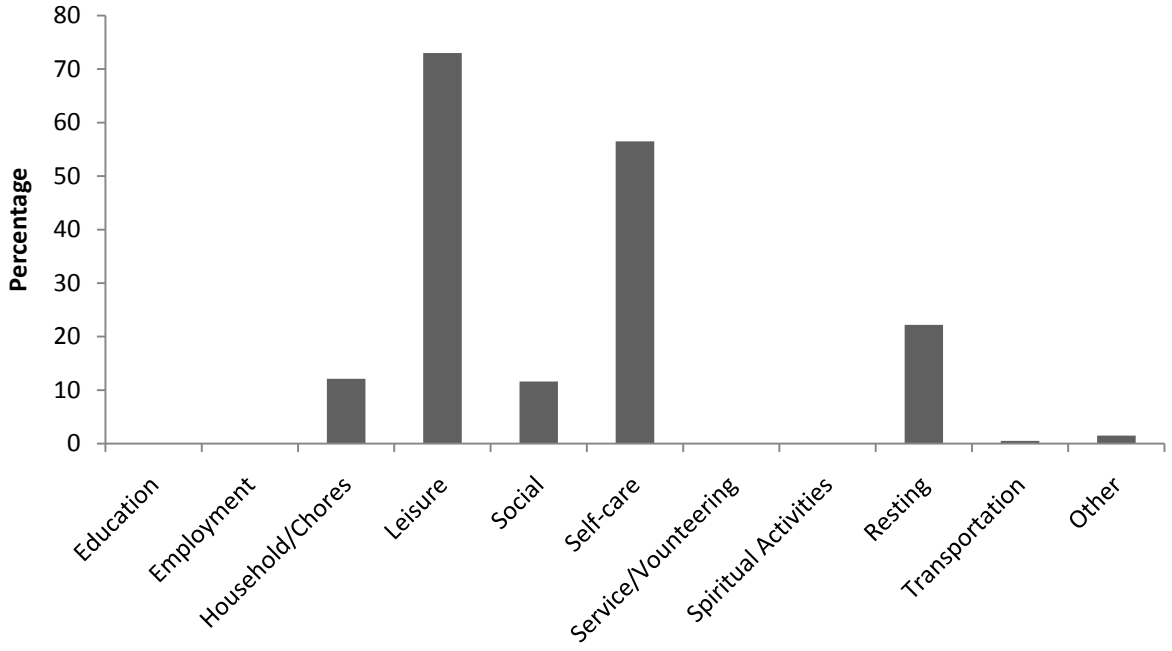


Figure 24. Types of Activities Engaged by Carmen.

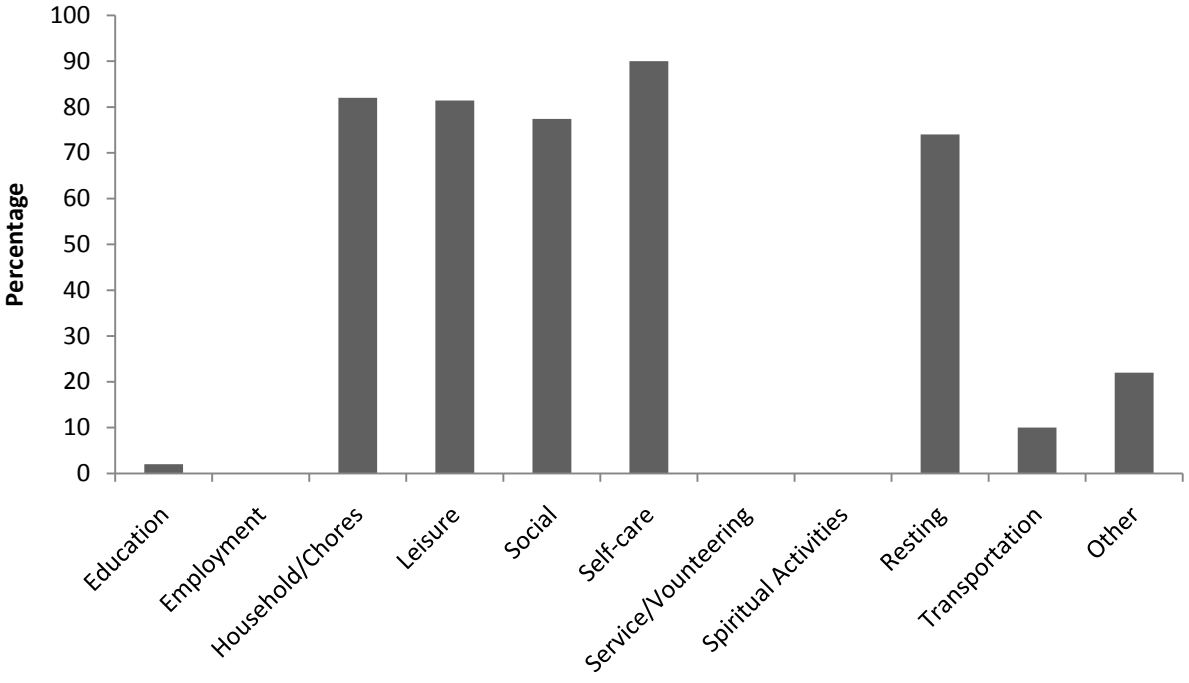


Figure 25. Types of Activities Engaged by Lilly.

Barriers and facilitators of community participation. Each participant reported on the barriers and facilitators of community participation during the feedback sessions. For Mark, cold temperatures and extreme weather conditions were the most frequently reported barriers to his participation. Other barriers included transportation, exhaustion and lack of energy due to diabetes, lack of motivation, and pain due to a foot injury. Facilitators that helped him engage in the community, identified during his feedback session were: making a plan ahead of time, watching the weather forecast before going out and having rides with PCA.

Carmen repeatedly mentioned transportation costs as her biggest barrier to community participation. She reported that being on a fixed income, she could not afford the $2.50 transportation fee each time she used the lift van, so she had to limit the number of outings. Thus, she chose only the necessary or important outings such as doctor's visits, counseling visits, and meetings with her daughter. Other barriers included lack of accessibility (e.g., bathrooms, door openers, store items on high shelves), mood and anxiety issues, health conditions, weather, limited options in community activities and lack of understanding by medical professionals. Facilitators included a friend's support, hospitality and assistance of people at the store and going out with her daughter. Carmen also reported that bus passes provided as one of the intervention components helped her tremendously. As a result, she decided to volunteer and went to the local volunteer center to seek volunteer opportunities.

Lilly reported cost of transportation, personal budget, pain, and other people's attitudes as her barriers to participation. The only facilitator she mentioned during the feedback session was having a PCA around while going out in the community. Lilly also told the researcher that the bus pass helped her go out and allowed her to engage in more social and leisure-related activities.

Social validity. At the end of the study, participants were asked to complete the social validity questionnaire and all three expressed satisfaction with the intervention procedures and outcomes. Overall, all three participants reported positive experiences regarding the intervention. A summary of the responses is presented in Appendix AC.

Reliability

Baseline data collection sessions. Two independent observers assessed the treatment integrity of the weekly feedback sessions by listening to recorded audio files of randomly selected sessions representing approximately one-third of all sessions in each condition and phase of the study, and filled out the reliability assessment form (Appendix AD). For the feedback sessions during the baseline condition, the overall agreement rate for Mark was 100%, for a total of one session. For Carmen, the overall agreement rate was 90%, for a total of two sessions. For Lilly, the overall agreement rate was 93.3%, for a total of three sessions.

Weekly feedback sessions. For the feedback sessions during the intervention condition, the overall agreement rate for Mark was 100%, for a total of eight sessions. For Carmen, the overall agreement rate was 97.9%, for a total of four sessions. For Lilly, the overall agreement rate was 100%, for a total of three sessions.

Discussion

The findings of Study 2 suggest that visual and oral feedback had some effect on increasing the frequency and duration of community participation for two of the three participants (Carmen and Lilly). For the remaining participant (Mark), a combination of visual and oral feedback, and a review of study goals was effective in boosting his community participation, particularly in terms of duration, which almost tripled from the baseline condition. In the end, the average frequency and duration of community participation was somewhat higher

than the baseline condition for all three participants. Although there was great variability in the data, trend lines from the cumulative duration graphs indicate that the direction of participants' data path changed when PDA self-monitoring and the visual and oral feedback was implemented (for Carmen and Lilly), or a review of study goals was implemented (for Mark). Mark and Lilly's figures show a slow and steady step-wise slope during baseline; however, the magnitude of this step-wise slope changed significantly, showing steeper upward lines after PDA self-monitoring and visual and oral feedback was implemented (for Lilly), or a review of study goal was implemented (for Mark).

Although Mark and Lilly went out less frequently than Carmen, the duration of time that they spent in the community increased noticeably. While daily frequency and duration data were variable, it is important to note that participants' ongoing personal and environmental variables such as financial hardship, weather, and health conditions likely affected the degree of their community participation. For example, Mark had four consecutive non-outing days after he injured his left foot significantly enough to require an emergency room visit. Additionally, Lilly reported that she was diagnosed with a spine infection which caused intense pain and reduced her activity level.

While there was no clear evidence, the data suggests that provision of bus passes facilitated more options and opportunities for participants to go out in the community, especially for Carmen. In an interview near the end of the study Carmen revealed that she used all 30 bus passes she received during the intervention. Subsequently, she reported only 0.07 % of days with two or more consecutive non-outings during the intervention condition. Lilly also mentioned that the bus passes gave her occasions to engage in non-medical related activities. Mark reported using only two bus passes during the study, citing two unpleasant incidents as contributors to his

decision not to use them. For example, he mentioned that a bus driver was not helpful in advising him of the correct bus stop locations and routes, resulting in Mark being late for an appointment. Mark preferred using his powerchair as a mode of transportation or having his PCA drive him when going out in the community.

Follow-up data showed that participants' community participation had decreased to sub-baseline levels four weeks after the study ended, with the exception of Lilly. There are several likely explanations for this reduction in community participation. First, the researcher's presence could have been an unintended independent variable, and the researcher's attention might have influenced participants' increased community participation behavior during the intervention. The literature suggests that attention can influence participant's behavior when it is given contingently (Hall, Lund & Jackson, 1986; Piazza, Bowman, Contrucci, Delia, Adelinis, & Goh, 1999) or non-contingently (Jones, Drew, & Webber, 2000; Hanley, Piazza, & Fisher, 1997; Derby, Fisher, & Piazza, 1996). Second, participants did not receive visual and oral feedback or any bus passes after the formal data collection ended. Carmen and Lilly had used all of their study-issued bus passes during the intervention. It is possible that Carmen and Lilly engaged in additional activities during the study intervention, since there was a reduced cost requirement for them to do so; however, when the study-issued bus passes were not available, they only engaged in necessary outings such as grocery shopping and medical appointments due to the inaffordability of transportation. Third, the follow-up data represent only eight days of retrospectively self-reported community participation. All participants reported challenges in recalling community participation activities and could not remember what they did more than three or four days ago. Since the intervention was withdrawn and the availability of the PDAs to capture data was not available, the ability of participants to accurately recall their community

outings was a challenge. Discussions on barriers and facilitators to community participation during the weekly feedback sessions yielded some valuable contextual information. These interviews allowed participants to express their concerns and allowed the researcher to address some of the identified barriers by modifying the intervention package. For example, the bus passes were included as an intervention component after each participant reported transportation as a barrier to community participation. Carmen later commented on the social validity survey form that a “free” bus pass helped her to get out in the community. She also gave positive feedback on the social validity survey about the identification of facilitators, which helped her to look at positive aspects of participation and recognize people who were helpful when she was out in the community.

With respect to the progress chart provided as visual feedback, Carmen and Lilly commented that the progress chart was not helpful in keeping track of their community participation progress while Mark felt it was useful. Lilly commented “I am not a math wiz”, suggesting that the progress chart was not accommodating or was difficult for her to interpret. Mark stated on the social validity survey that the study helped him to know how active he was and made him aware of what he does. Mark and Carmen reported that oral feedback was helpful in identifying barriers and facilitators of their community participation.

As in Study 1, using a PDA to self-monitor participant’s community participation exemplifies an innovative method of measuring behavior in naturalistic settings. All three participants had a high completion rate (e.g., Mark = 98.8 %, Carmen = 98.9%, Lilly = 99.3%). Participants were also asked to submit permanent products related to their community participation; however, the submission rate of these products was variable across participants (e.g., Mark = 49.1%, Carmen = 14.6%, Lilly = 60.5%). It was challenging for participants to

provide a permanent product for each outing that they made. For example, Carmen often engaged in outdoor activities, such as visiting someone else's home and going to trail/lake/forest, where no permanent product was available. She was also required to collect her receipts and submit them to social rehabilitation services to continue receiving benefits. Banks were one of the most frequently visited sites for all participants, but they declined to use their bank slips as permanent products due to privacy issues.

Social validity survey results showed that two of the three participants were satisfied with ease of the PDA entry process while one participant felt very satisfied or 4, on a scale of 1-5. Regarding the frequency of the PDA entries required for this study (four times a day and seven days a week), two participants reported neutral or 3 while one participant marked satisfied or 4, on a scale of 1 to 5. Overall, participants gave positive ratings regarding PDA use and completion of the community participation survey which required a response four times daily. Given these responses, using the Personal Digital Assistance (PDA) to collect data on participants' community participation proved to be feasible in capturing and providing more real-time information about participants' behavior.

The study has a number of limitations. First, the repeated case study design used in this study has potential threats to both internal and external validity. Originally, a multiple-baseline across participants design was planned. However, the case design study was substituted for three reasons: (a) accommodating extensive consecutive non-outings during the visual and oral feedback condition for Mark, (b) avoiding participant attrition, and (c) individualizing the intervention package given the complexity and diversity of participants' barriers and facilitators. The ABC and ABCD designs used in this study do not control for participants' history, maturation, selection, or mortality. Therefore, it is difficult to demonstrate a more causal

relationship and to avoid control for possible extraneous variables. There also may have also been a seasonal effect. The study started in early February and concluded at the end of April. Since the weather was reported by participants to be one potential barrier to community participation, precipitation and varying temperatures may have affected the degree of community participation. Second, the results from the study may have limited generalization due to a small sample size and age range. Study 2 included three participants who experienced severe physical disabilities, were middle-aged, had low-incomes, were public assistance beneficiaries, had secondary health issues, experienced substantial barriers to public transportation, and lived in an urban community.

Another limitation is the use of self-report data and lack of data verification. Baseline and follow-up data solely relied on the retrospective self-report. Although participants were prompted to save permanent products at each meeting, the submission rate was significantly lower than in Study 1. The literature notes that self-reported data is often subject to recall bias and accuracy concerns (Brandburn, Rips & Shevell, 1987; Shiffman et al., 2008). The limitation of self-report data use and lack of data verification may sacrifice some research rigor; however, participants made efforts to provide permanent products when these items were available to them.

The baseline measures of Study 2 must be viewed with some caution as there were two different approaches. More specifically, the measurement of community participation was changed from the retrospective written self-report to the PDA self-monitoring during the first baseline one and second baseline. The data suggest that in addition to measuring participant's outings, the PDA also may have functioned as a prompting device. Put another way, participants' frequency and duration of behavior showed modest behavior change when the PDA was introduced.

While our decision to provide four scheduled PDA prompts daily instead of the six daily random promptings used by Seekins et al., (2007) was made to avoid response fatigue and to increase the PDA completion rate, it restricted our ability to randomly capture “live information”. For example, participants accessed their PDAs at each scheduled prompt and answered a short survey to report activities they engaged in the past three hours. Participants could select multiple locations, activities, social contexts, and report total duration and overall satisfaction of those activities. Therefore, it was difficult to determine how long participants spent, what activities they engaged at where, their satisfaction and social context at each and specific community location. It possibly masked data and limited an understanding of what happened at a specific time and place.

Another limitation was scheduling and the time of the meetings. The researcher usually visited participants’ homes or preferred community locations (i.e., library) twice weekly to download data from their PDA. These meetings usually occurred at the same time for each participant (i.e., 12:30 p.m. for Mark, 1:15 p.m. for Carmen and 2:00 p.m. for Lilly), which might have hindered participants from going out in the community before or after these meetings. It is also possible that these meetings might have set the occasion for going out into the community due to the researcher’s visit and presence. In Study 1, this was not considered to be a limitation issue since the researchers resided in the community where the study was conducted, and it was possible to be flexible in accommodating the participants’ schedules for data collection meetings. Even though Study 2 participants did not articulate concerns about meeting times, it is important to note that the twice weekly meetings might have interfered and affected participant’s community participation when planning activities ahead of time.

The study has a number of strengths. It was conducted in participants' natural environments. While there were some methodological limitations (i.e., self-reports, experimental design) and logistical restrictions (i.e., observations and meeting schedules), the current study reconfirmed the utility of EMA to measure a complex set of community participation behaviors of people with mobility-related disabilities.

Study 2 explored numerous variables to engage participants in increased community participation. The researcher attempted to increase the desired target behavior by introducing new independent variables such as bus passes and review of study goals on a case by case basis. Decisions to implement these independent variables were guided and determined by the continuous visual inspection of data and considered participants' personal and environmental characteristics.

Participants showed increases in the frequency and duration of their community outings. During the follow-up interview participants provided comments on the meaningfulness of their increased community participation. When the researcher asked participants "What does participation mean to you? What does it mean to participate?" Mark stated "as superficial as it sounds, it makes you kind of feel like you are a part of the community." He also commented that participation means "just going out and doing something… choosing what to do, and having independence". Carmen reported "I guess being involved and participating… and getting back to the community." Lily's response was "basically just going out and getting what I need here in the house." These comments confirm the notion that community participation is both a means and an end to achieve personal interests and contribute to their community. They also reflect themes associated with participation values shown in the Figure 1 on page 4. Five of the six themes (meaningful engagement/being a part of, personal and societal responsibilities, having an

impact and supporting others, social connection, inclusion and membership, choice and control) contributing to participation values were identified by the current study participants. It supports the assertion by Hammel et al., (2008) that community participation can take different forms and shapes and conveys purposes that are unique to each individual. The findings of Study 2 also validate that subjective experience and values are important measures of community participation. Qualitative interviews added more depth and provided stories about what community participation means to study participants.

Implication for future research

Both studies contribute to the body of literature regarding the measurement of community participation of people with mobility-related disabilities. The first study suggests that training and peer support might be necessary but not sufficient to achieve increased community participation. Moreover, use of PDAs seemed to have unexpectedly functioned as a prompting device and affected participants' community participation.

The second study suggests that visual and oral feedback facilitated some increased community participation when combined with barrier removal and review of study goals. Even though the results of these studies were not significant and conclusive, they provide a platform of ideas for future studies on community participation of people with disabilities.

Future studies could benefit from including both objective and subjective data measures. Subjective measures of participation are critical to understand the full meaning of participation (Wade & Halligan, 2003) and illustrate the unique experience of people with disabilities (Hammel, et al., 2008). Subjective measures provide useful information on how people's attitudes and environmental features shape the experience of community participation. Empirically validated surveys such as the Facilitators And Barriers Survey (FAB) (Gray et al.,

2008) and the Survey of Participation And Receptivity in Communities (SPARC) (Gray & Hollingsworth, 2010) could be administered to capture the subjective data regarding community participation and to learn how perceived barriers and facilitators can minimize or maximize the degree of community participation.

Although bus passes helped participants to increase their options when selecting sites for community visits by reducing transportation costs, provision of bus passes lasted for only a short time during the intervention. Therefore, it was difficult to examine the long-term effects and benefits of bus passes on increased and sustained community participation. Future studies might examine a relationship between transportation usage and community participation. Transportation interventions such as the Traveler's Cheque voucher program (Gonzales, Stombauch, Seekins, & Kansnitz, 2006) could be implemented to provide low-cost and sustainable accessible transportation for people with disabilities who live in rural communities. In addition, researchers might consider using a contextual-behavior model of empowerment (Fawcett et al., 1994) to create empowerment opportunities and increase the capacity of individuals by removing or reducing environmental barriers.

The current study included a small sample of people who have mobility-related disabilities. Future studies might compare community participation across people with different disability types, socio-economic conditions, ages, racial and ethnic groups, and community groups to determine what factors affect community participation of people with disabilities. For example, energy, pain, disability type, and self-efficacy were found to be the most important predictors of participation in a study of young adults with physical disability (Bent, Jones, Molloy, Chamberlain, & Tennant, 2001), whereas, depression played a role in the relationship between pain and community participation of people with traumatic brain injuries (Hoffman,

Pagulayan, Zawaideh, Dikmen, Tempkin, & Bell, 2007). With more detailed information and specific focus on demographic and contextual variables, researchers might develop an intervention package that meets the needs of people with specific types of disabilities.

It is also important to consider the practicality of study procedures and the sustainability of desired outcomes. Future studies should incorporate state-of-art technology such as the iPhone, other “smart phones” or a PDA with built-in GPS feature to collect data and gather evidence of real-time and location of community participation activities. These technologies would increase the validity of data and allow more flexibility for both participants and the researchers when collecting data. With respect to sustainability, the researcher might consider offering transition and adaptation phases where both the researcher and participants discuss mid-term and long-term goals and objectives to maintain initiated efforts and collaboration. Community research and action values outlined by Fawcett (1991) stress replicability and sustainability of interventions through local resources, and effective dissemination. The researchers might communicate and collaborate with local disability organizations such as CILs to implement and sustain research efforts and to build partnerships that support enhanced and increased community participation of consumers with disabilities.

Conclusion

Community participation is both a means and an end to achieve meaningful lives for all citizens. Community participation gives choice and control to individuals and enables people with disabilities to become agents of change for fostering a more inclusive and accessible community. To make this a reality, there needs to be collaborative efforts and actions at the individual, organizational, societal and political levels. More importantly, people with disabilities need to take the initiative and exert leadership in addressing their rights and needs.

The two studies described in this paper offer strategies to measure and increase community participation for people with mobility-related disabilities. Further research in this area will help us to better understand and examine community participation of people with disabilities, and how their participation can further strengthen the capacity of communities and create opportunities to enhance their personal levels of independence and empowerment.

References

Alavosius, M. P., & Sulzar-Azaroff, B. (1986). The effects of performance feedback on the safety of client lifting and transfer. *Journal of Applied Behavioral Analysis*, 19(3), 261-267.

Austin, J., Weatherly, N. L., & Gravina, N. E. (2005). Using task clarification, graphic feedback, and verbal feedback to increase closing-task completion in a privately owned restaurant. *Journal of Applied Behavior Analysis*, 38(1), 117-120.

Baker, S. M., & Kaufman-Scarborough, C. (2001). Marketing and public accommodation: A retrospective on Title III of the Americans with Disabilities Act. *Journal of Public Policy & Marketing*, 20(2), 297-304.

Barker, R. N., Kendall, M. D., Amsters, D. I., Perouse, K. J., Haines, T. P., & Kuipers, P. (2009). The relationship between quality of life and disability across the lifespan for people with spinal cord injury. *Spinal Cord*, 47, 149-155.

Balcazar, F. E., Seekins, T., Fawcett, S. B., & Hopkins, B. L. (1990). Empowering people with physical disabilities through advocacy skills training. *American Journal of Community Psychology*, 18(2), 281-296.

Bekker, M. J., Cumming, T. D., Osborne, N. K., Bruining, A. M., McClean, J. I., & Leland, L.S. (2010). Encouraging electricity saving in a university residential hall through a combination of feedback, visual prompts, and incentives. *Journal of Applied Behavior Analysis*, 43(2), 327-331.

Bent, N., Jones, A., Molloy, I., Chamberlain, M.A., & Tennant A. (2001). Factors determining participation in young adults with a physical disability: A pilot study. *Clinical Rehabilitation*, 15, 552-561.

Brandburn, N., Rips, L., & Shevell, S. (1987). Answering autobiographical questions: The impact of memory and influence on surveys. *Science*, 236, 157-161.

Brobst, B., & Ward, P (2002). Effects of public posting, goal setting, and oral feedback on the skills of female soccer players. *Journal of Applied Behavior Analysis*, 35(3), 247-257.

Brown, S. H, Lewis, C.A, McCarthy, J., Doyle, S, Hurvitz, E. A. (2009). The effects of internet-based home training on upper limb function in adults with cerebral palsy. *Neurorehabilitation and Neural Repair*, 24(6), 575-583.

Campbell, D. T., & Stanley, J. C. (1963). *Experimental and quasi-experimental designs for research*. Boston: Houghton Mifflin.

Carpenter, C., Forwell, S. J., Jongbloed, L. E. & Backman, C. L. (2007). Community participation after spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 88, 427-433.

Chenoweth, L., & Stehlik, D. (2004). Implications of social capital for the inclusion of people with disabilities and families in community life. *International Journal of Inclusive Education*, 8(1), 59-72.

Codding, R. S., Feinberg, A. B., Dunn, E. K., & Pace, G. M. (2005). Effects of immediate performance feedback on implementation of behavior support plans. *Journal of Applied Behavior Analysis*, 38(2), 205-219.

Coleman-Martin, M. B., & Heller, K. W. (2004). Using a modified constant prompt-delay procedure to teach spelling to students with physical disabilities. *Journal of Applied Behavior Analysis*, 37, 469-480.

Condeluci, A. (2008). *Together is Better: Creating a community where each person belongs.* Wake Forest, NC: Lash & Associate Publishing/Training Inc.

Condeluci, A. (1999). *Essence of Interdependence*. Baco Raton, FL: CRC Press.

Critchfeld, T. S. (1999). An unexpected effect of recording frequency in reactive self-monitoring. *Journal of Applied Behavior Analysis*, 32(3), 389-391.

Curran, S. L., Beacham, A. O., & Andrykowski, M. A. (2004). Ecological momentary assessment of fatigue following breast cancer treatment. *Journal of Behavioral Medicine*, 27(5), 425-444.

Derby, K. M., Fisher, W. W., & Piazza, C. C. (1996). The effects of contingent and noncontingent attention on self-injury and self-restraint. *Journal of Applied Behavior Analysis,* 29, 107-110.

Dijkers, M. P. (2010). Issues in the conceptualization and measurement of participation: An Overview. *Archives of Physical Medicine and Rehabilitation*, 92(1), S5-16.

Dijkers, M. (1998). Community integration: Conceptual issues and measurement approaches in rehabilitation research. *Topics in Spinal Cord Injury Rehabilitation*, 4(1), 1-15.

Dunton, G. F., Whalen, C. K., Jamner, L., D., Henker, B., & Floro, J., N. (2005). Using ecologic momentary assessment to measure physical activity during adolescence. *American Journal of Preventive Medicine,* 29(4), 281-287.

Fawcett, S. B. (1991). Some values guiding community research and action. *Journal of Applied Behavior Analysis,* 24, 621-636.

Fawcett, S. B., White, G.W., Balcazar, F. E., Suarez-Balcazar, Y., Mathews, M. R., & Paine-Andrews, A. (1994). A contextual-behavioral model of empowerment: Case studies involving people with physical disabilities. *American Journal of Community Psychology*, 22(4), 471-496.

Gonzales, L., Stombauch, D., Seekins, T., Kasnitz, D. (2006). Accessible rural transportation: An

evaluation of the Traveler's Cheque voucher program. *Journal of Community Development*, 37(3), 106-115.

Gray, D., & Hollingsworth, H. (October, 2010). *Measures for assessing community participation.* [PowerPoint Slides]. Paper presented at State of the Science Conference, Overland Park, KS. Retrieved from, http://www.rtcil.org/micl/State%20of%20Science%20conf/R1%20Measures%20for%20Assessing%20Community%20Participation.pdf

Gray, D., & Dashner, J. L. (October, 2010). *Excellence in PAS: Measures and training Materials* [PowerPoint Slides]. Paper presented at State of the Science Conference, Overland Park, KS. Retrieved from, http://www.rtcil.org/micl/State%20of%20Science%20conf/R4%20Excellence%20in%20PAS.pdf

Gray, D., & Hollingsworth, H., Stark., & Morgan, K. A. (2008). A subjective measure of environmental facilitators and barriers to participation for people with mobility limitations. Disability and Rehabilitation, 30(6), 434-457.

Gray, D., Hollingsworth, H., Stark, S., & Morgan, K. (2006). Participation Survey/Mobility: Psychometric properties of a measure of participation for people with mobility impairments and limitations. *Archives of Physical Medicine and Rehabilitation*, 87, 189-197.

Gray, D. B., Gould, M., & Bickenbach, J. E. (2003). Environmental barriers and disability. *Journal of Architectural and Planning Research*, 20(1), 29-37.

Hagglund, K. J., Clark, M. J., Schopp, L. H., Sherman, A. K., & Acuff, M. E. (2005). Consumer-assistant education to reduce the occurrence of urinary tract infections among persons with spinal cord injury. *Topics in Spinal Cord Injury*, 10(3), 53-62.

Hall, R. V., Lund, D., & Jackson, D. (1968). Effects of teacher attention on study behavior.

Journal of Applied Behavior Analysis, 1, 1-12.

Hammel, J., Magashi, S., Heinemann, A., Whiteneck, G., Bogner, J. & Rodriguez, E. (2008). What does participation mean? An insider perspective from people with disabilities. *Disability and Rehabilitation*, 30(19), 1445-1460.

Hammel, J., Jones, R., Gossett, A., & Morgan, E. (2006). Examining barriers and supports to community living and participation after a stroke from a participatory action research approach, *Topics in Stroke Rehabilitation*, 13(3), 43-58.

Hanley, G. P., Piazza, C. C., & Fisher, W. W. (1997). Noncontingent presentation of attention and alternative stimuli in the treatment of attention-maintained destructive behavior. *Journal of Applied Behavior Analysis*, 30, 229-237.

Harris, F., Sprigle, S., Sonenblum, S. E., & Maurer, C. L. (2010). The participation and activity measurement system: An example application among people who use wheel mobility devices. *Disability and Rehabilitation: Assistive Technology*, 5(1), 48-57.

Hay, L. R., Nelson, R. O., & Hay, W. M. (1980). Methodological problem in the use of participant observers. *Journal of Applied Behavior Analysis*, 13(3), 501-504.

Hayes, S. C., & Cone, J. D. (1981). Reduction of residential consumption of electricity through simple monthly feedback. *Journal of Applied Behavior Analysis*, 14, 81-88.

Helliwell, J.E. (2001). Social capital, the economy and well-being. In K. Banting, A. Sharpe & F. St. Hilaire (Eds). *The Review of Economic Performance and Social Progress.* Montreal, Canada: Institute for Research on Public Policy and Centre for the Study of Living Standards.

Herbert, J., & Smith, B. (1997) Improving living standards through social capital. *Social Security Journal*, December, 33-60.

Hoffman, J. M., Pagulayan, K. F., Zawaideh, N., Dikemen, S., Tempkin, N., & Bell, K. (2007). Understanding pain after traumatic brain injury: Impact on community participation. *American Journal of Physical Medicine & Rehabilitation*, 86(12), 962-969.

Houten, R. V., Hill, S., & Parsons, M. (1975). An analysis of a performance feedback system: The effects of timing and feedback, public posting, and praise upon academic performance and peer interaction. *Journal of Applied Behavioral Analysis*, 8(4), 449-457.

Hufford, M. R., & Shiffman, S. (2002). Methodological issues in affecting the value of patient-reported outcomes data. *Expert Review of Pharmacoeconomics & Outcomes Research*, 2(2), 119-128.

Hughes, R. B., Nosek, M. A., Howland, C. A., Groff, J. Y., & Mullen, P. D. (2003). Health promotion for women with physical disabilities: A pilot study. *Rehabilitation Psychology*, 48(3), 182-188.

Hyyppä, M. T., & Mäki, J. (2003). Social participation and health in a community rich in stock of social capital. Health Education Research, 18(6), 770-779.

Jones, K. M., Drew, H. A., & Weber, N. L. (2000). Noncontingent peer attention as treatment for disruptive classroom behavior. *Journal of Applied Behavior Analysis,* 33, 343-346.

Kessler Foundation & National Organization on Disability (2010). *The ADA, 20 years later*. Retrieved on June 5, 2011, from http://www.2010disabilitysurveys.org/pdfs/surveysummary.pdf

Kirby, K. C., Flower, S. A., & Baer, D. (1991). Reactivity in self-recording: Obtrusiveness of recoding procedure and peer comments. *Journal of Applied Behavior Analysis*, 24(3), 487-498.

Lingo, A. S., Jolivette, K. & Barton-Arwood, S. M. (2009). Visual and oral feedback to promote

appropriate social behavior for a student with emotional and behavioral disorders. *Preventing School Failure*, 54(1), 24-29.

Maisel, J. L. (2006). Toward inclusive housing and neighborhood design: A look at visitability. *Community Development*, 37, 26-34.

Mead, S., Hilton, D., & Curtis, L. (2001). Peer support: A theoretical perspective, *Psychiatric Rehabilitation Journal*, 25, 134-141.

McClain, L., Medrano, D., Marcum, M., & Schukar, J. (2000). A qualitative assessment of wheelchair user's experience with ADA compliance, physical barriers, and secondary health conditions. *Topics in Spinal Cord Injury Rehabilitation*, 6(1), 99-118.

Meyers, A. R., Anderson, J. J., Miller, D. R., Ship, K., & Hoenig, K. (2002). Barriers, facilitators, and access for wheelchair users: Substantive and methodologic lessons from a pilot study of environmental effects. *Social Science & Medicine*, 55, 1435-1446.

Mitchell, D., & Harrison, M. (2001). Studying employment initiatives for people with mental health problems in developing countries: A research agenda. *Primary Health Care Research and Development*, 2, 107-116.

Nafukkho, F. M., Roessler, R. T., & Kacirek, K. (2010). Disability ad a diversity factor: Implications for human resource practices. *Advances in Developing Human Resources*, 12(4), 395-406.

National Organization on Disability & Harris Interactive, Inc. (2000). *2000 survey of community participation.* Retrieved June 5, 2011, from http://nod.org/research_publications/nod_harris_survey/2000_survey_of_community_participation/

Newman, S. D. (2010). Evidence-based advocacy: Using photovoice to identify barriers and

facilitators to community participation after spinal cord injury. *Rehabilitation Nursing*, 35(2), 47-59.

Oxford, M., & McDonald, G. (1999). Two paths—One journey: Ending oppression… one accessible step at a time. Topeka: Kansas Department of Health and Environment.

Pendragon Forms (Version 5.1). [Computer software]. Buffalo Grove, IL: Pendragon Software Corporation.

Piazza, C. C., Bowman, L. G., Contrucci, S. A., Delia, M. D., Adelinis, J. D., & Goh, H. (1999). An evaluation of the properties of attention as reinforcement for destructive and appropriate behavior. *Journal of Applied Behavior Analysis*, 32, 437-449.

Putnam, R. D. (1995). Bowling alone: American's declining social capital. *Journal of Democracy*, 6(1), 65-78.

Ravesloot, C., Seekins, T., & White, G. (2005). *Living Well with a Disability* health promotion intervention: Improved health status for consumers and lower costs for health care policymakers. *Rehabilitation Psychology*, 50 (3), 239-245.

Ravesloot, C., H., Seekins, T., Cahill, T., Lindgren, S., Nary, D. E., & White, G. (2006). Health promotion for people with disabilities: development and evaluation of the *Living Well with a Disability* program. *Health Education Research*, 22(4), 522-531.

Seekins, T., Enders, A., Pepper, A., & Sticka, S. (2007). Allocation and use of Section 5310 funds in urban and rural American. *Journal of Public Transportation*, 10, 81-101.

Seekins, T., Ipsen, C., & Arnold, N. L. (2007). Using ecological momentary assessment to measure participation: A preliminary study. *Rehabilitation Psychology*, 52(3), 319-330.

Shiffman, A., Stone, A. A., & Hufford, M. R. (2008). Ecological momentary assessment. *Annual Review of Clinical Psychology*, 4, 1-32.

Shiffman, S., Gwaltney, C. J., Balabanis, M., Liu, K.S., Party, J.A., . . . Gnys, M. (2002). Immediate antecedents of cigarette smoking: An analysis from ecological momentary assessment. *Journal of Abnormal Psychology*, 111(4), 531-45.

Sigurdsson, S. O., & Austin, J. (2008). Using real-time visual feedback to improve posture at computer workstations. *Journal Applied Behavior Analysis*, 42(3), 365-375.

Sigurdsson, S. O., & Austin, J. (2008). Using real-time visual feedback to improve posture at computer workstations. *Journal of Applied Behavior Analysis*, 41(3), 365-375.

Smyth, J., Wonderlich, S., Crosby, R., Miltenberger, R., Mitchell, J., & Rorty, M. (2001). The use of ecological momentary assessment approach in eating disorder research. *The International Journal of Eating Disorders*, 30(1), 83-95.

Solomon, P. (2004). Peer support/peer provided services underlying processes, benefits, and critical elements. *Psychiatric Rehabilitation Journal*, 27, 392-401.

Stone, A., Broderick, J. E., Schwartz, J. E., Shiffman, S., Litcher-Kelly, A., & Calvanese, P. (2003). Intensive momentary reporting of pain with an electronic diary: Reactivity, compliance, and patient satisfaction. *Pain*, 104, 314-351.

Taylor, H. (2005). *Many people with disabilities feel isolated, left out of their communities and would like to participate more: The more severe the disability the greater the isolation.* Retrieved April 7, 2011, from http://www.harrisinteractive.com/vault/Harris-Interactive-Poll-Research-MANY-PEOPLE-WITH-DISABILITIES-FEEL-ISOLATED-LEFT-O-2000-07.pdf.

The Rural Institute (2009). *Living Well with a Disability*. Missoula, University of Montana Rural Institute.

Trap, J. J., Milner-Davis, P., Joseph, S., & Cooper, J. O. (1978). The effects of feedback and

consequences on transitional cursive letter formation. *Journal of Applied Behavioral Analysis,* 11(3), 381-393.

Ulicny, G. R., Adler, A. B., Kennedy, S. E., & Jones, M. L. (2006). *A step-by-step guide to training and managing personal assistants: Consumer guide.* Lawrence, KS: Research and Training Center on Independent Living, University of Kansas.

U.S. Department on Health and Human Services (2010). *Healthy People 2020: Disability and Health*, Retrieved May 26, 2011, from http://www.healthypeople.gov/2020/ topicsobjectives2020/objectiveslist.aspx?topicId=9

U.S. Department of Labor, Bureau of Labor Statistic (2011, May). *Employment Situation Archived News Release,* Retrieved from, http://www.bls.gov/schedule/archives/ empsit_nr.htm#2010

Wade, D. T., & Halligan, P. (2003). New wine in bottles: the WHO ICF as an explanatory model of human behavior. *Clinical Rehabilitation*, 17, 349-354.

World Health Organization. (2001). *International classification of functioning, disability and health*. Geneva, Switzerland: Author.

White, G. W., Gonda, C., Peterson, J., & Drum, C. (2011). Secondary analysis of a scoping review of health promotion interventions for persons with disabilities: Do health promotion interventions for people with mobility impairments address secondary condition reduction and increased community participation? *Journal of Disability and Health, 4, 129-139.*

White, G. W., Simpson, J. L., Gonda, C., Coble, Z., & Ravesloot, C. (2010). Moving from

independence to interdependence: A conceptual model for better understanding community participation of centers for independent living consumers. *Journal of Disability Policy Studies,* 20(4), 223-240.

White, G. W. & Vo, Y., T. (2006). Requesting accommodations to increase full participation in higher education: An analysis of self-advocacy training for postsecondary students with disabilities. *Learning Disabilities: A Multidisciplinary Journal, 14*(1), 41-56.

White, G. W., Paine-Andrews, A., Mathews, R. M., & Fawcett, S. B. (1995). Home access modifications: Effects on community visits by people with physical disabilities. *Journal of Applied Behavior Analysis*, 28(4), 457-463.

Whiteneck, G. G., Charlifue, S. W., Gerhart, K. A., Overhosler, J. D., & Richardson, G. N. (1992), Quantifying handicap: A new measure of long-tern rehabilitation outcomes. *Archives of Physical Medicine and Rehabilitation*, 73, 519-526.

Willer, B., Ottenbacher, K. J., & Coad, M. L. (1994). Community integration questionnaire: A comparative examination. *American Journal of Physical Medicine and Rehabilitation,* 73, 103-111.

Yoshiuchi, K., Yamamoto, Y., & Akabayashi, A. (2008). Application of ecological momentary assessment in stress-related diseases. *BioPsychoSocial Medicine*, 2(1), 13-18.

Appendix A

Get Out & About! Training Manual

Note: Due to a size of this material, it is not included in the Appendix section. A copy of this material is available on the web at: https://documents.ku.edu/xythoswfs/webview/fileManager?stk=A0083F00D940683&entryName=%2Fusers2%2Fchiaki%2FChiaki+Gonda+Thesis+Materials&msgStatus=.

Appendix B

Get Out & About! Training Manual Reviewer Evaluation Form

Chapter 1 Goal Setting

Evaluation Form

Reviewer Name: _____ Date: _____

1. Was Chapter 1 clear and understandable?

   Yes No

2. Did Chapter 1 use language/vocabularies that would make sense to most people with disabilities?

   Yes No

3. Was information presented in a logical order?

   Yes No

4. Was the format (i.e., text size/graphs/charts/tables/clip art pictures) of the chapter appropriate?

   Yes No

5. Did Chapter 1 have enough easy-to-understand examples that are related to people who have mobility related disabilities?

   Yes No

6. On a scale of 1-5, how would you rate your overall impression of Chapter 1? (1= poor 2= needs some work, 3= neutral 4= good, 5= well done!)

   1 2 3 4 5

What did you like about Chapter 1?

What did you not like about Chapter 1?

What are some suggestions to improve Chapter 1?

Chapter 2: Problem Solving

Evaluation Form

Reviewer Name: _____ Date: _____

1. Was Chapter 2 clear and understandable?

   Yes No

2. Did Chapter 2 use language/vocabularies that would make sense to most people with disabilities?

   Yes No

3. Was information presented in a logical order?

   Yes No

4. Was the format (i.e., text size/graphs/charts/tables/clip art pictures) of the chapter appropriate?

   Yes No

5. Did Chapter 2 have enough easy-to-understand examples that are related to people who have mobility related disabilities?

   Yes No

6. On a scale of 1-5, how would you rate your overall impression of Chapter 2? (1= poor 2= needs some work, 3= neutral 4= good, 5= well done!)

   1 2 3 4 5

7. What did you like about Chapter 2?

8. What did you not like about Chapter 2?

9. What are some suggestions to improve Chapter 2?

Chapter 3: Information Seeking

Evaluation Form

Reviewer Name: _____ Date: _____

1. Was Chapter 3 clear and understandable?

   Yes No

2. Did Chapter 3 use language/vocabularies that would make sense to most people with disabilities?

   Yes No

3. Was information presented in a logical order?

   Yes No

4. Was the format (i.e., text size/graphs/charts/tables/clip art pictures) of the chapter appropriate?

   Yes No

5. Did Chapter 3 have enough easy-to-understand examples that are related to people who have mobility related disabilities?

   Yes No

6. On a scale of 1-5, how would you rate your overall impression of Chapter 3? (1= poor 2= needs some work, 3= neutral 4= good, 5= well done!)

   1 2 3 4 5

7. What did you like about Chapter 3?

8. What did you not like about Chapter 3?

9. What are some suggestions to improve Chapter 3?

Chapter 4: Advocacy

Evaluation Form

Reviewer Name: _____ Date: _____

1. Was Chapter 4 clear and understandable?

   Yes No

2. Did Chapter 4 use language/vocabularies that would make sense to most people with disabilities?

   Yes No

3. Was information presented in a logical order?

   Yes No

4. Was the format (i.e., text size/graphs/charts/tables/clip art pictures) of the chapter appropriate?

   Yes No

5. Did Chapter 4 have enough easy-to-understand examples that are related to people who have mobility related disabilities?

   Yes No

6. On a scale of 1-5, how would you rate your overall impression of Chapter 4? (1= poor 2= needs some work, 3= neutral 4= good, 5= well done!)

   1 2 3 4 5

7. What did you like about Chapter 4?

8. What did you not like about Chapter 4?

9. What are some suggestions to improve Chapter4?

On a scale of 1-5, how would you rate your overall impression of the ***Get Out and About*** training manual? (1= poor 2= needs some work, 3= neutral 4= good, 5= well done!)

1 2 3 4 5

If you have any questions or suggestions, please write down in the space below.

Appendix C

PDA Handbook

Note: Due to a size of this material, it is not included in the Appendix section. A copy of this material is available on the web at: https://documents.ku.edu/xythoswfs/webview/fileManager?stk=A0083F00D940683&entryName=%2Fusers2%2Fchiaki%2FChiaki+Gonda+Thesis+Materials&msgStatus=.

Appendix D

Get Out & About! Training Pre and Posttest

Get out and About! Training Workshop

Pre/Post Test

(____/15)

Name: _____ Date: _____

Chapter 1: Goal Setting

Part A: Knowledge Testing

1. Identify the order of the steps you should take when selecting your goals. (1 point)

   ___Write a goal statement, objectives and actions plans

   ___ Look at your past, present, and future.

   ___ Name a life goal to work on.

2. Match the types of goals on the left with the examples to the right. Draw a line matching the category on the left with the correct answer on the right. (3points)

Small Goal	Take guitar lessons
Medium Goal	Participate in a guitar performance
Large Goal	Collect guitar music

3. Choose and circle 5 of the most important things to consider when selecting your goal. (5 points)

   Easy Specific Medium Achievable Generic

   Realistic Cost-effective Satisfying Measurable Small

   Ambitious Time-based Big Unique Vague Personal

4. Fill in the blank. (1 point)

A statement of your objective should specify _____.

Part B: Application Question

1. Write a goal statement related to your community participation. (5points)

_____

_____

_____

_____

_____

Chapter 2: Problem Solving (____/15)

Part A: Knowledge Testing

1. True or False? Please circle T or F to indicate your response to the statements below. (4 points)

T F Problem solving is an opportunity to learn your weaknesses and shortcomings.

T F Problem solving begins with a positive attitude.

T F Seeking peer support is important when solving problems.

T F Asking for help is the last thing you should do. You can only feel satisfied when you can solve a problem by yourself.

2. Fill in the blank. (1 point)

What do you call the following effect? Solving one problem helps to solve a similar problem, which then will cause another similar change. _____ effect

3. Match the examples of specific problems on the left with the types of problem to the right. Draw a line matching the examples on the left with the correct category on the right. (5 points)

Problems	**Types**
• I avoid meeting new people because I feel self-conscious.	Environmental
• Going out makes me tired.	Environmental
• I want to go to a knitting club but the building isn't accessible.	Personal
• City transit doesn't run after 8 pm.	Environmental and Personal
• I want to hire a personal care attendant, but I cannot afford to pay.	Personal

Part B. Application Question

Jen's goal is to find a part-time job by the end of summer. She applied for a secretarial position at an office, but she didn't get the job because she doesn't know how to use a computer (i.e., Word, Excel, Internet). (5 points)

a. Identify the environmental and personal barriers that are affecting Jen's chances for getting a job.

- Environmental Barrier:

- Personal Barrier:

b. Write down a list of things Jen can work on to solve her problems.

Environmental:
Personal:

Chapter 3: Information Seeking (____/20)

Part A: Knowledge Testing

1. True or False? Please circle T or F to indicate your choice. (5 points)

T F Collecting information is easy. Everybody knows how to seek information.

T F Information can be found in many people, places and things.

T F Obtaining enough information is all you need to make informed choices regarding your options.

T F You cannot collect data from more than 5 information sources because it will confuse you.

T F Seeking information is an active process that can help you reach your goal.

2. Choose and circle 4 important things you need to consider when evaluating information. (4 points)

Relevant Believable Original Often cited Information Source

Contradictory Timely Professional Understandable

3. Match the types of change or situation category on the left with the examples to the right. Draw a line matching the category on the left with the correct example on the right. (6 points)

Change or Situation Category	**Examples**
Changing daily activities	You continue to advocate for accessible parking spaces at your apartment complex.
Improving changes you've already begun	You received a notice that you could lose your home or apartment.
Sudden, dramatic changes repeat themselves	You will start participating in a weekly book reading club.
Sudden, dramatic, first-time changes	You want to go back to school and get a degree.
Small changes pile up to cause a problem	You need to replace a wheelchair every 5 years.
How you think or feel about change	Your shoulder pain got worse and now you need a personal care attendant to assist with daily chores.

Part B. Application Question

Jen wants to find an accessible house that is near the public bus route. Identify the information Jen needs and where/who is the best source for the information she needs. (5 points)

What Information?	What Source?

Chapter 4: Advocacy (____/15)

Part A: Knowledge Testing

1. True or False? Please circle T or F to indicate your choice. (4 points)

T F Complaining to your friend about a lack of accessible equipment at the local gym is one type of self-advocacy.

T F There is only one approach to self-advocacy.

T F Writing an advocacy letter is an effective way to make a change in the environment.

T F Peer support can help you decide whether self-advocacy can help solve a barrier.

2. Match the advocacy steps on the left with the approaches to the right. Draw a line matching the category on the left with the correct answer on the right. (6 points)

Advocacy Steps	Approaches
Seek useful information	Reflect on your experience and identify barriers to your goal.
Communicate clearly	Don't give up on your goals. Stay focused and keep trying or take a different approach.
Take care of yourself	Tell your story and make your request believable and reasonable.
Identify the need	Start with a small step and adjust as you solve problems.
Be patient and don't get discouraged	Do not let your advocacy steps tire you in reaching your goal. Watch your health conditions and problems.
Identify the solvable problem	Provide the restaurant owner information about tax credits for accessibility improvements.

Part B. Application Question

You went to a grocery store and saw somebody's bicycle parked in the accessible parking spot, so you couldn't park your van there. It was the second time you saw that happening. How would you advocate to solve this problem? Write down your action plan. (5 points)

What was the key disability concern?
How did the problem affect you?
Who or what is the cause of this problem?
Does this problem occur frequently or rarely?
Is there any law in existence that can be used?

Appendix E

Focus Group Consent Form

Focus Group

INFORMED CONSENT STATEMENT

Name of the Study

Testing an information and skills training package to increase community participation for consumer with mobility limitations.

INTRODUCTION

The Department of Applied Behavioral Science at the University of Kansas supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you wish to participate in the present study. You may refuse to sign this form and not participate in this study. You should be aware that even if you agree to participate, you are free to withdraw at any time. If you do withdraw from this study, it will not affect your relationship with this unit, the services it may provide to you, or the University of Kansas.

PURPOSE OF THE STUDY

The purpose of this study is to assess the levels community participation by people with disabilities living in the community, and to learn what barriers people with disabilities face and strategies they have used to more fully participate in the community.

PROCEDURES

You will be asked to complete a short survey with close-ended questions. This should take between 5-15 minutes. Following this, the researcher will ask you to participate in a focus group where you and other consumers will be asked a series of open-ended questions that invite your own thoughts and perspectives about your participation in the community. This interview is expected to take between 60-90 minutes, and with your permission, be tape recorded.

RISKS

We don’t anticipate any burdens, inconveniences, pain, discomforts and risks associated with participation in the study.

BENEFITS

We cannot guarantee that participation in the focus will be beneficial to you. However, we believe that your participation can help us to learn about barriers and facilitators of community participation for people with disabilities.

PAYMENT TO PARTICIPANTS

You will receive a $30 gift card for your participation in this focus group. After completion of the survey and interview, you will be given some brief paperwork to fill out. You will need to give your social security number in order for us to give you a gift card.

PARTICIPANT CONFIDENTIALITY

Your name will not be associated in any way with the information collected about you or with the research findings from this study. The researcher(s) will use a study number or a pseudonym (false name) instead of your name. The researchers will not share information about you unless required by law or unless you give written permission.

By signing this form you give permission for the use and disclosure of your information for purposes of this study at any time in the future.

INSTITUTIONAL DISCLAIMER STATEMENT

N/A

REFUSAL TO SIGN CONSENT AND AUTHORIZATION

You are not required to sign this Consent and Authorization form and you may refuse to do so without affecting your right to any services you are receiving or may receive from the University of Kansas or to participate in any programs or events of the University of Kansas. However, if you refuse to sign, you cannot participate in this particular study.

CANCELING THIS CONSENT AND AUTHORIZATION

You may withdraw your consent to participate in this study at any time. You also have the right to cancel your permission to use and disclose information collected about you, in writing, at any time, by sending your written request to: [Chiaki Gonda, Graduate Research Assistant, Research and Training Center on Independent Living, University of Kansas, 1000 Sunnyside Avenue, Dole Center, Room 4089, Lawrence, KS 66045]. If you cancel permission to use your information, the researchers will stop collecting additional information about you. However, the research team may use and disclose information that was gathered before they received your cancellation, as described above.

QUESTIONS ABOUT PARTICIPATION

Questions about procedures should be directed to the Chiaki Gonda listed at the end of this consent form.

PARTICIPANT CERTIFICATION:

I have read this Consent and Authorization form. I have had the opportunity to ask, and I have received answers to, any questions I had regarding the study. I understand that if I have any additional questions about my rights as a research participant, I may call (785) 864-7429 or (785) 864-7385 or write the Human Subjects Committee Lawrence Campus (HSCL), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7563, email dhann@ku.edu or mdenning@ku.edu.

I agree to take part in this study as a research participant. By my signature I affirm that I am at least 18 years old and that I have received a copy of this Consent and Authorization form.

_____ _____

Type/Print Participant's Name Date

_____

Participant's Signature

I also agree to be tape recorded for this focus group meeting.

_____ _____

Type/Print Participant's Name Date

_____

Participant's Signature

Researcher Contact Information

Chiaki Gonda	Glen W. White, Ph.D.
First Investigator	Faculty Supervisor
Dept of Applied Behavioral Science	Dept. of Applied Behavioral Science
4089 Dole Bldg	4089 Dole Bldg
1000 Sunnyside Ave.	1000 Sunnyside Ave.
University of Kansas	University of Kansas
Lawrence, KS 66045	Lawrence, KS 66045
785-864-4095	785-864-4095
chiaki@ku.edu	glen@ku.edu

Appendix F

Focus Group Close-Ended Survey

Close-Ended Survey

1. Are you Male ____ or Female_____?

2. How old are you? _____

3. What is your disability? _____

   (※ If you have two or more disabilities, which one of your disabilities affect your community participation?)

4. Number of years since acquiring your disability _____

5. Do you use a mobility device or other assistive technology to get around?

   _____ Yes _____ No

   5a. What types of mobility device do you use?

   _____ Manual Wheelchair

   _____ Power Wheelchair

   _____ Scooter

   _____ Cane

   _____ Walker

   _____ Crutches

   _____ Segway

   _____ Other assistive device (please specify _____)

6. Where do you live? (Please check only one)

   ____ Own House

   ____ Rent House

   ____ Apartment/Townhouse/Condominium

____ Parent's or other relative's home

____ Cooperative Housing

____ Assisted Housing

_____Other (please specify _____)

7. Who do you live with? (Check all that apply)

____ Alone

_____ A spouse or significant other

_____ Children (how many?_____)

_____ Other relative (how many? _____)

_____ Roommate or housemate (how many? _____)

_____ Other (please specify _____)

8. How much assistance, if any, are you currently receiving with activities of daily living (bathing, dressing, eating etc.) on a weekly basis?

___ None or not applicable

___ 1-10 hours per week

___ 11-30 hours per week

___ 31-40 hours per week

___ More than 40 hours per week

9. Who provides this assistance?

___ Self-directed Personal Care Attendant

___ Agency directed Personal Care Attendant

___ Spouse/Significant other

___ Other family members

___ Friends

___ Other

___ Not applicable

10. What is the highest grade in school you completed?

___ Grade School

___ Elementary School

___ High School Graduate

___ Associate's Degree

___ Bachelor's Degree

___ Master's Degree

___ Completed other graduate degree (Ph.D., J.D., M.D., D.O., etc)

___ Technical School (e.g., cosmetology, legal assistant)

___ Other (please specify _____)

11. What is your current employment status? (check all that apply).

___ Not currently employed

___ Employed part-time

___ Employed full-time

___ Volunteer

___ Retired

___ Homemaker

12. Please estimate your annual household income

___ $0-$9,999

___ $10,000 -$14,999

___ $15,000-$19,999

___$20,000-$24,999

___$25,000-$29,999

___$30,000-$49,999

___$50,000 or more

13. How many times per week do you typically go out in the community (besides work)?

14. Besides work, where do you typically go when you leave your home? (Check all that apply)

___ Grocery Store

___ Restaurant

___ Bar

___ Shopping

___ Entertainment Facilities (i.e. Movie, Sport, Museum, etc)

___ Friends and Family's house

___ Religious Facilities

___ Library

___ Educational facilities

___ Parks and recreation sites

___ Hospitals/Clinics/Physical Therapy

___ Run errands at the bank, post office, etc

___ Salon/Barber shop

___ Other (Please specify _____)

15. Who do you often go out with? (Check all that apply)

____ By myself

____Friends

____Family

____Spouse/Partner/Significant others

____PCA

____Pet

____ Other (Please specify _____)

16. What transportation do you use when you go out?

___ My own vehicle

___ Family or relative's vehicle

___ Friend's vehicle

___ My PCA's vehicle

___ City Transit

___ Para Transit

___ Rental Car

___ Taxi

___ Other (please specify _____)

17. Are you currently experiencing a secondary condition?

___ Yes ___ No

17a (check all that apply)

___UTI

___Fatigue

___Pressure sore

___Depression

___Other(s) (please specify _____)

18. If you are to receive a training, what topics are you interested in learning?

(**Please choose 4 topics from the list**)

_____ Goal Setting

_____ Problem Solving

_____ Responding to Frustrations with Health Reactions

_____ Beating the Blues

_____ Healthy Communication

_____ Seeking Information

_____ Physical Activity

_____ Nutrition

_____ Advocacy

_____ Other (Please specify _____)

Thank you for completing the survey!!

Appendix G

Focus Group Open-Ended Questions

Focus Group Open-ended Questions

1. What are some factors in your personal life that prevent you from community participation?

2. What are some factors in your environment that prevent you from community participation?

3. What are some things that increase your community participation?

4. How often do you participate in community activities? If so, when, where, how long, with whom?

5. Are your activities in the community usually spontaneous or pre-planned (e.g., going to the show, going shopping)? Give examples.

6. Where/how do you get information about activities?

7. What things move you from contemplating doing an activity to actually doing the activity?

8. What things might encourage you to participate in a new activity more frequently?

9. What does community participation mean to you?

10. What things could a CIL do to increase your participation?

11. How satisfied are you with your current level of community participation?

12. If you could change one thing in your life to enhance your community participation, what would it be?

13. Have you received a workshop or training about community activities (e.g., recreation, sports, hobby)?

14. What strategies do you use to become more involved in the community?

Appendix H

Study 1 Recruitment Flyer

Want to learn how to get involved in the community?

Enroll in a research study at Research and Training Center on Independent Living at the University of Kansas

If you enroll in a study you will:

- receive 4 two-hour workshops free (Workshop topics include: goal setting, problem solving, information seeking and advocacy)
- learn knowledge and skills to enhance your community participation
- be asked to keep track of your daily activities
- receive monetary reward up to $250 for participating in the research study

Eligibility - Individuals with physical disabilities who meet ALL the criteria below:

- have a mobility related disability as a primary disability
- are between age 18-65
- are living in the community (not a group home/institution)
- can arrange transportation to come to the trainings
- can commit up to a 8-10 week study
- are not presently working in a full-time job

(*Your participation will be determined after a phone interview with the research staff)

If you are interested in participating in this study, please call Chiaki Gonda, graduate research assistant, at 785-864-4095 or email at chiaki@ku.edu

Appendix I

Screening Phone Survey

Screening Questions for Prospective Research Participants

Applicant's Name_____

Phone Number _____

1a. Do you have a disability affecting your mobility that limits your major life activities such as dressing, bathing, getting in/out of home, etc?

□Yes (GO TO #1b) □ No

1b. What is your (primary) mobility-related disability?

Note: _____

1c. Do you use any mobility device, such as a wheelchair, scooter, walker or cane?

□Yes □ No

If yes, what type of device do you use? _____

1d. How long has it been since you acquired your mobility-related disability?

Note: _____

2. Are you at least 18 years old but not older than 65?"

□Yes (GO TO #3) □ No

3. Do you live in the community and not in an institution or group home setting?

□Yes (GO TO #4) □ No

4. Are you able to give informed consent (agree on your own to enroll in the study and do NOT require a legal guardian to make this decision for you)?

□ Yes (GO TO #5) □ No

5a Do you currently have a paid job?

□ Yes □ No (GO TO #5b)

Is if a full-time or a half-time?

___ Full-Time ___ Half-Time ____Other (i.e., less than half-time)

5b. Do you currently have a non-paid job? (Volunteer)

□ Yes □ No

If yes, how many hours a week do you spend on this non-paid job?

_____

6. Do you have a significant sensory disability (related to vision or hearing) that requires you to obtain or provide information by alternate formats (such as Braille or use of a sign

language interpreter)?

□ Yes □ No (GO TO #7)

If yes, what is the nature of your sensory disability? (e.g., hear of hearing, blind)

Note: _____

What accommodation do you need? (e.g., Large print materials, ASL interpreter, Braille, audio)

Note: _____

7. Do you have a traumatic brain injury, head injury, or any type of cognitive impairment that affects your ability to organize and process information?

□ Yes □ No (GO TO #8)

8. Do you have any serious health problem or severe/frequent secondary conditions that could affect your participation in the community? (e.g., UTI, pressure sore, severe fatigue)

□Yes □ No

Note: _____

9a. Have you ever used Personal Digital Assistance (PDA) device before?

□ Yes □No (GO TO #9b)

9b. Are you able to operate a PDA device and enter data using a stylus without the assistance of others?

□ Yes (GO TO #10) □ No

10. Are you a native English speaker?

□ Yes (GO TO #11) □ No

11. Can you arrange transportation to come to the trainings and meetings in Lawrence weekly?

□Yes (GO TO #11) □ No

12a. Can you commit up to 10 weeks to participate in this study? (By agreeing to participate in the study, you are expected to come to 4 training sessions, meet with the researcher twice a week and perform assigned tasks.) It is expected start in late-March or early April.

□Yes (GO TO #13a) □ No (GO TO #12b)

12b. How many weeks can you participate if not 10 weeks?

_____

13a. Are you currently receiving services from disability-related service agencies (e.g., Independent Living Center, Vocational Rehabilitation)?

□Yes (GO TO #13b) □ No

13b. If so, where and how long have you been receiving this (these) service(s)?

Note: _____

14a. Have you ever received any training related to community participation (e.g., advocacy, employment, IL skills training) in the past?

□Yes (GO TO #14b) □ No (GO TO #15)

14b. If yes, what kind of training have you received and when/by whom?

What_____

When_____

By Whom _____

15a. Do you know how to use the internet?

□Yes (Go TO #15b) □ No

15b. Do you have the internet access at home?

□Yes □ No

15c. Do you have an email account?

□Yes □ No

Thank you for answering questions! We will be in touch to advise you of your eligibility for the study. If you would like more information about the study, please contact Chiaki Gonda at the Research and Training Center on Independent Living, University of Kansas, 785-764-495 or chiaki@ku.edu

Appendix J

Pre-Enrollment Survey

Pre-Enrollment Survey

1. Are you Male ____ or Female_____?
2. How old are you? _____
3. What is your race/ethnicity?

   (Check all that apply)

   ☐ American Indian/Alaska Native

   ☐ Asian

   ☐ Black/African American

   ☐ Native Hawaiian/Other Pacific Islander

   ☐ White

   ☐ Other(specify) _____

   ☐ I prefer not to answer
4. Are you: (Check all that apply)

   ☐*Married* ☐*Separated* ☐*I prefer not to answer*

   ☐*Divorced* ☐*Never been married*

   ☐*Widowed* ☐*Member of an unmarried couple*
5. What is your disability? _____

   (※ If you have two or more disabilities, which one of your disabilities affects your community participation?)

   Number of years since acquiring your disability _____
6. Do you use a mobility device or other assistive technology to get around?

   _____ Yes _____ No

If yes, what types of mobility device do you use?

_____ Manual Wheelchair

_____ Power Wheelchair

_____ Scooter

_____ Cane

_____ Walker

_____ Crutches

_____ Segway

_____ Other assistive device (please specify _____)

7. Where do you live? (Please check only one)

____ Own House

____ Rent House

____ Apartment/Townhouse/Condominium

____ Parent's or other relative's home

____ Cooperative Housing

____ Assisted Housing

_____Other (please specify _____)

8. Who do you live with? (Check all that apply)

_____ Alone

_____ A spouse or significant other

_____ Children (how many?_____)

_____ Other relative (how many? _____)

_____ Roommate or housemate (how many? _____)

_____ Other (please specify _____)

9. How much assistance, if any, are you currently receiving with activities of daily living (bathing, dressing, eating etc.) on a weekly basis?

___ None or not applicable

___ 1-10 hours per week

___ 11-30 hours per week

___ 31-40 hours per week

___ More than 40 hours per week

10. Who provides this assistance?

___ Self-directed Personal Care Attendant

___ Agency directed Personal Care Attendant

___ Spouse/Significant other

___ Other family members

___ Friends

___ Other

___ Not applicable

11. Which of the following benefits are you **currently** receiving?

(Check all that apply.)

☐*Social Security Benefits (SSI, SSDI or SS retirement)*

☐*Medicare*

☐*Medicaid*

☐*Services from an Independent Living Center*

☐*None of the above*

☐*I prefer not to answer*

12. What is the highest grade in school you completed?

___ Grade School

___ Elementary School

___ High School Graduate

___ Associate's Degree

___ Bachelor's Degree

___ Master's Degree

___ Completed other graduate degree (Ph.D., J.D., M.D., D.O., etc)

___ Technical School (e.g., cosmetology, legal assistant)

___ Other (please specify _____)

13. What is your current employment status? (check all that apply).

___ Not currently employed

___ Employed part-time

___ Employed full-time

___ Volunteer

___ Retired

___ Homemaker

14. How many times per week do you typically go out in the community (besides work)?

15. Besides work, where do you typically go when you leave your home? (Check all that apply)

___ Grocery Store

___ Restaurant/Cafe

___ Bar

___ Shopping

___ Entertainment Facilities (i.e. Movie, Sport, Museum, etc)

___ Friends and Family's house

___ Religious Facilities

___ Library

___ Educational facilities

___ Parks and recreation sites

___ Hospitals/Clinics/Physical Therapy

___ Run errands at the bank, post office, etc

___ Salon/Barber shop

___ Other (Please specify _____)

16. Who do you often go out with? (Check all that apply)

____By myself

____Friends

____Family

____Spouse/Partner/Significant others

____PCA

____Pet

____ Other (Please specify _____)

17. What transportation do you use most when you go out?

___ My own vehicle

___ Family or relative's vehicle

___ Friend's vehicle

___ My PCA's vehicle

___ City Transit

___ Para Transit

___ Rental Car

___ Taxi

___ Other (please specify _____)

18. Do you consider yourself active in community participation?

____ No

____ Somewhat No

____ Somewhat Yes

____ Yes

19. On a scale of 1-5, how satisfied are you with your current level of community participation?

___ 1 Not at all satisfied

___ 2 Not Satisfied

___ 3 Somewhat satisfied

___4 Satisfied

___ 5 Very satisfied

20. What types of activities make you happy or fulfilled? Check three items from below categories.

___ Educational

___ Entertainment (e.g., movie, concert, game, TV)

___ Hobby (e.g., painting, knitting, cooking, computer)

___ Outdoor activities/Recreation/Leisure (e.g., hiking, walking, camping)

___ Physical exercise (e.g., workout, swimming, playing tennis)

___ Shopping/Eat Out

___ Socializing with friends/family/peers

___ Spiritual/Meditation/Religious

___ Volunteering/Service

___ Other (Please specify _____)

21. Are you currently experiencing a secondary condition?

___ Yes ___ No (check all that apply)

___Urinary Tract Infection

___Fatigue

___Pressure sore

___Depression

___Other(s) (please specify_____)

Thank you for taking the survey!

Appendix K

Study 1 Consent Form

Effectiveness Study – Pilot Test

INFORMED CONSENT STATEMENT

Name of the Study

Information and skills training to enhance community participation of people with mobility limitations.

INTRODUCTION

The Department of Applied Behavioral Science at the University of Kansas supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you wish to participate in the present study. You may refuse to sign this form and not participate in this study. You should be aware that even if you agree to participate, you are free to withdraw at any time. If you do withdraw from this study, it will not affect your relationship with this unit, the services it may provide to you, or the University of Kansas.

PURPOSE OF THE STUDY

The purpose of this project is to evaluate an information and skills training package to enhance community participation of people with disabilities. It will also assess the barriers people with disabilities face and strategies they have used to more fully participate in the community.

PROCEDURES

This section will explain what you will be asked to do if you enroll in the study.

LENGTH OF THE STUDY

The length of this study is expected to last between 8-12 weeks.

Personal Digital Assistant (PDA)

You will be provided a personal digital assistant (PDA) device and will be asked to carry the PDA with you wherever you go. Before the study begins, you will be taught how to operate a PDA. Technical assistance will be available throughout the study period by phone or email.

- The PDA will make a gentle sound and prompt you four times each day at 12pm, 3pm, 6pm and 9pm.
- At each prompt, you access to the PDA and enter answers to several questions
- It will take about one minute to answer the questions
- The researcher will collect your data twice a week
- Upon completion of study, the PDAs will be returned to the researcher.

Note: Please answer the questions as soon as it is possible to do so. It should not disturb your activity or schedule. You can delay the data entry if the prompting sound occurs during an important event or conversation (i.e. driving a car, in doctor's office, emergency). If you can not enter data immediately, please do so as soon as you are able.

Camera

You will also be provided and trained on how to use a camera which you will use to record your activity or location. This photo will provide additional data for the study.

- Each time you visit a different place(s) in the community, please take a photo of your activity and/or place
- The researcher will collect your photos each week
- Upon completion of study, the camera will be returned to the researcher.

Permanent Products

You will be asked to save any permanent products associated with your outings (i.e., receipts, tickets, brochures, Drs. Appointment cards, etc)

- Please save receipts, tickets, brochures (if you have any) in the provided envelope
- The researcher will collect them weekly, make copies and send them back to you, if you wish.

Training

You will be required to attend two-day training workshop during the study period.

- You will receive an notification in advance of the training session
- You will be responsible for obtaining your own transportation to come to the training
- The training will cover the topics of Goal Setting, Problem Solving, Information Seeking and Advocacy
- Training materials will be provided by the researcher
- During the training you will engage in some skill practice and discussion
- Each training will last 5 hours including working lunch

RISKS

We don't anticipate any burdens, inconveniences, pain, discomforts or risks to be associated with participation in the study.

BENEFITS

Participants can learn skills that may lead to increased and enhanced community participation.

PAYMENT TO PARTICIPANTS

You will have an opportunity to earn up to $250. The amount of monetary reward you can receive will be determined by your PDA completion rate and length of your participation in the study. The money you earned will be paid at the end of the study or when you withdraw from the study.

If your PDA completion rate is more than 90% throughout the study, you will receive the full amount ($250). If your PDA completion rate is between 70-89%, you will receive half of the amount ($125.50). If your PDA completion rate is below 70%, you will receive one-fourth of the amount ($62.50) See chart below

Payment Chart

PDA completion rate	90%-100%	70%-89%	Below 70%
Pilot Study	$250	$125.50	$62.50

If you decide to withdraw from the study or stop attending the scheduled meetings and/or performing assigned tasks, your monetary rewards will be re-calculated and adjusted based on the number of weeks you have completed and your PDA completion rate during the weeks you participated.

You will also receive a $5 for each time you attend a training session and a meeting.

You will be asked to complete some brief paperwork to fill out and you will need to give your social security number in order for us to give you a gift card.

PARTICIPANT CONFIDENTIALITY

Your name will not be associated in any way with the information collected about you or with the research findings from this study. The researcher(s) will use a number or a pseudonym instead of your name. The researchers will not share information about you unless required by law or unless you give written permission. **[The researcher will not share photos that you have taken or other permanent products that were collected during the study without your explicit permission.]**

INSTITUTIONAL DISCLAIMER STATEMENT

N/A

REFUSAL TO SIGN CONSENT AND AUTHORIZATION

You are not required to sign this Consent and Authorization form and you may refuse to do so without affecting your right to any services you are receiving or may receive from the University of Kansas or to participate in any programs or events of the University of Kansas. However, if you refuse to sign, you cannot participate in this study.

CANCELNG THIS CONSENT AND AUTHORIZATION

You may withdraw your consent to participate in this study at any time. You also have the right to cancel your permission to use and disclose information collected about you, in writing, at any time, by sending your written request to: [Chiaki Gonda, Graduate Research Assistant, Research and Training Center on Independent Living, University of Kansas, 1000 Sunnyside Avenue, Dole Center, Room 4089, Lawrence, KS 66045]. If you cancel permission to use your information, the researchers will stop collecting additional information about you. However, the research team may use and disclose information that was gathered before they received your cancellation, as described above.

QUESTIONS ABOUT PARTICIPATION

Questions about procedures should be directed to Chiaki Gonda. Her contact information is listed at the end of this consent form.

PARTICIPANT CERTIFICATION:

I have read this Consent and Authorization form. I have had the opportunity to ask, and I have received answers to, any questions I had regarding the study. I understand that if I have any additional questions about my rights as a research participant, I may call (785) 864-7429 or (785) 864-7385 or write the Human Subjects Committee Lawrence Campus (HSCL), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7563, email mdenning@ku.edu.

I agree to take part in this study as a research participant. By my signature I affirm that I am at least 18 years old and that I have received a copy of this Consent and Authorization form.

_____ _____

Type/Print Participant's Name Date

_____

Participant's Signature

I give my permission to use the photographs I have taken as part of this study, for research purposes.

_____ _____

Type/Print Participant's Name Date

_____

Participant's Signature

I also agree to be audiotaped and/or video recorded during the training sessions and weekly meetings.

_____ _____

Type/Print Participant’s Name Date

_____

Participant’s Signature

Researcher Contact Information

Chiaki Gonda
First Investigator
Dept. of Applied Behavioral Science
4089 Dole Bldg
1000 Sunnyside Ave.
University of Kansas
Lawrence, KS 66045
785 864 4095
chiaki@ku.edu

Glen W. White, Ph.D.
Faculty Supervisor
Dept. of Applied Behavioral Science
4089 Dole Bldg
1000 Sunnyside Ave.
University of Kansas
Lawrence, KS 66045
785 864 4095
glen@ku.edu

Appendix L

PDA Mastery Test

PDA Entry Practice Test

Scenario 1

You went to HyVee with your spouse to buy some groceries. On the way back home, you stopped at the gas station and filled a gas. You were out in the community about an hour. You felt slightly satisfied about this activity.

Circle on the most appropriate answer.

1: Did you go out in the past three hours? Yes No

2: Where did you go in the past three hours?

Your choices are (check as many as apply):

- Car or bus *(either public or private)*
- Entertainment facility *(e.g., movie theater, bowling alley, zoo, theme park)*
- Grocery/Drug store *(e.g., Wal-mart, Dillons, CVS, Walgreens)*
- Gym/exercise facility
- Hospital/health care provider *(defined as hospital, doctor's office, rehab facility, dentist, etc.)*
- Home
- Office building *(defined as government or private. i.e. library, post office, bank)*
- Park/forest
- Public sidewalk
- Religious facility
- Restaurant/café/bar
- Retail store *(e.g. business establishment such as department store, mall, car dealer, coin laundry, gas station)*
- School *(university, community college, middle-school, high-school, etc)*
- Someone else's home
- Other

3: What kind of activity (or activities) did you engage in?

Your choices are (check as many as apply):

- Education *(e.g., taking classes, doing homework, on-line workshops/tutorials, reading textbook)*
- Employment *(defined as seeking, paid full-time work, paid half-time/hourly work)*

- Household/chores *(defined as housework, grocery shopping, childcare, household shopping, house improvements, meal preparation, paying bills, upkeep and maintenance)*
- Leisure *(defined as arts/culture, ceremony, club activity, computer, crafts/hobbies, gardening, games, playing music, talking on phone, reading, clothes shopping, sports, television)*
- Social *(e.g., chatting with friends, going to a party, attending, eating out with friends/family/peer/co-workers).*
- Self-care *(defined as exercise, grooming, medical appointments, other appointments, health related shopping)*
- Service/volunteering *(defined as unpaid work - e.g., babysitting friend's child)*
- Spiritual activities (*e.g., praying, attending faith service, meditating)*
- Resting *(defined as sleeping, napping, sitting quietly)*
- Transportation *(defined as driving, being a passenger, walking, wheeling, biking)*
- Other

4: Who did you primarily do this activity (or these activities) with?

Your choices are (check as many as apply):

- Alone
- Business person *(e.g., sales person, insurance agent, store clerk)*
- Personal care attendant
- Family
- Friends
- Mixed group
- Peers/Coworkers
- Pets
- Professionals
- Significant other (*defined as your spouse, partner, girl/boy friend)*
- Strangers
- Other

5: If you went out in the community, how long were you out?

Your choices are (Please choose only 1 answer):

- Less than 30 min.
- 30 min. to 1 hour
- 1-2 hours
- 2-3 hours
- N/A *(Not applicable – in other words, you did not go out in the community)*

6: On a scale of 1-5, how would you rate overall satisfaction with this (these) activity (activities)?

Tap the scale on a number between 1 and 5 where:

1 = Dissatisfied

2 = Slightly dissatisfied

3 = Neutral

4 = Slightly satisfied

5 = Satisfied

7: Reminders – Make sure to keep your permanent products associated with your outings and to take a photo of your activities when you go out!

- **What types of permanent products do you use to prove your activities? Write as many as you can think of. (Write "Not Applicable" if you stayed in your home for the past three hours)**

Scenario 2

You stayed home alone resting in your bed for the past 3 hours. While resting, you watched some TV, listened to music. You didn't feel satisfied because you were bored in the bed.

Circle on the most appropriate answer.

1: Did you go out in the past three hours? Yes No

2: Where did you go in the past three hours?

Your choices are (check as many as apply):

- Car or bus *(either public or private)*
- Entertainment facility *(e.g., movie theater, bowling alley, zoo, theme park)*
- Grocery/Drug store *(e.g., Wal-mart, Dillons, CVS, Walgreens)*
- Gym/exercise facility
- Hospital/health care provider *(defined as hospital, doctor's office, rehab facility, dentist, etc.)*
- Home
- Office building *(defined as government or private. i.e. library, post office, bank)*
- Park/forest
- Public sidewalk
- Religious facility

- Restaurant/café/bar
- Retail store *(e.g. business establishment such as department store, mall, car dealer, coin laundry, gas station)*
- School *(university, community college, middle-school, high-school, etc)*
- Someone else's home
- Other

3: What kind of activity (or activities) did you engage in?

Your choices are (check as many as apply):

- Education *(e.g., taking classes, doing homework, on-line workshops/tutorials, reading textbook)*
- Employment *(defined as seeking, paid full-time work, paid half-time/hourly work)*
- Household/chores *(defined as housework, grocery shopping, childcare, household shopping, house improvements, meal preparation, paying bills, upkeep and maintenance)*
- Leisure *(defined as arts/culture, ceremony, club activity, computer, crafts/hobbies, gardening, games, playing music, talking on phone, reading, clothes shopping, sports, television)*
- Social *(e.g., chatting with friends, going to a party, attending, eating out with friends/family/peer/co-workers).*
- Self-care *(defined as exercise, grooming, medical appointments, other appointments, health related shopping)*
- Service/volunteering *(defined as unpaid work - e.g., babysitting friend's child)*
- Spiritual activities (*e.g., praying, attending faith service, meditating)*
- Resting *(defined as sleeping, napping, sitting quietly)*
- Transportation *(defined as driving, being a passenger, walking, wheeling, biking)*
- Other

4: Who did you primarily do this activity (or these activities) with?

Your choices are (check as many as apply):

- Alone
- Business person *(e.g., sales person, insurance agent, store clerk)*
- Personal care attendant
- Family
- Friends
- Mixed group
- Peers/Coworkers
- Pets
- Professionals
- Significant other (*defined as your spouse, partner, girl/boy friend)*
- Strangers
- Other

5: If you went out in the community, how long were you out?

Your choices are (Please choose only 1 answer):

- Less than 30 min.
- 30 min. to 1 hour
- 1-2 hours
- 2-3 hours
- N/A *(Not applicable – in other words, you did not go out in the community)*

6: On a scale of 1-5, how would you rate overall satisfaction with this (these) activity (activities)?

Tap the scale on a number between 1 and 5 where:

1 = Dissatisfied

2 = Slightly dissatisfied

3 = Neutral

4 = Slightly satisfied

5 = Satisfied

7: Reminders – Make sure to keep your permanent products associated with your outings and to take a photo of your activities when you go out!

- **What types of permanent products do you use to prove your activities? Write as many as you can think of. (Write "Not Applicable" if you stayed in your home for the past three hours)**

Scenario 3

You left your home at 9:30am because you had a doctor's appointment at 10am. On the way home, you stopped by at the Walgreen and got your prescribed drugs. You got home around 11:30am. You satisfied because you finally had a chance to talk with your doctor about your health condition.

Circle on the most appropriate answer.

1: Did you go out in the past three hours? Yes No

2: Where did you go in the past three hours?

Your choices are (check as many as apply):

- Car or bus *(either public or private)*
- Entertainment facility *(e.g., movie theater, bowling alley, zoo, theme park)*
- Grocery/Drug store *(e.g., Wal-mart, Dillons, CVS, Walgreens)*
- Gym/exercise facility
- Hospital/health care provider *(defined as hospital, doctor's office, rehab facility, dentist, etc.)*
- Home
- Office building *(defined as government or private. i.e. library, post office, bank)*
- Park/forest
- Public sidewalk
- Religious facility
- Restaurant/café/bar
- Retail store *(e.g. business establishment such as department store, mall, car dealer, coin laundry, gas station)*
- School *(university, community college, middle-school, high-school, etc)*
- Someone else's home
- Other

3: What kind of activity (or activities) did you engage in?

Your choices are (check as many as apply):

- Education *(e.g., taking classes, doing homework, on-line workshops/tutorials, reading textbook)*
- Employment *(defined as seeking, paid full-time work, paid half-time/hourly work)*
- Household/chores *(defined as housework, grocery shopping, childcare, household shopping, house improvements, meal preparation, paying bills, upkeep and maintenance)*
- Leisure *(defined as arts/culture, ceremony, club activity, computer, crafts/hobbies, gardening, games, playing music, talking on phone, reading, clothes shopping, sports, television)*
- Social *(e.g., chatting with friends, going to a party, attending, eating out with friends/family/peer/co-workers).*
- Self-care *(defined as exercise, grooming, medical appointments, other appointments, health related shopping)*
- Service/volunteering *(defined as unpaid work - e.g., babysitting friend's child)*
- Spiritual activities (*e.g., praying, attending faith service, meditating)*
- Resting *(defined as sleeping, napping, sitting quietly)*
- Transportation *(defined as driving, being a passenger, walking, wheeling, biking)*
- Other

4: Who did you primarily do this activity (or these activities) with?

Your choices are (check as many as apply):

- Alone
- Business person *(e.g., sales person, insurance agent, store clerk)*
- Personal care attendant
- Family
- Friends
- Mixed group
- Peers/Coworkers
- Pets
- Professionals
- Significant other (*defined as your spouse, partner, girl/boy friend)*
- Strangers
- Other

5: If you went out in the community, how long were you out?

Your choices are (Please choose only 1 answer):

- Less than 30 min.
- 30 min. to 1 hour
- 1-2 hours
- 2-3 hours
- N/A *(Not applicable – in other words, you did not go out in the community)*

6: On a scale of 1-5, how would you rate overall satisfaction with this (these) activity (activities)?

Tap the scale on a number between 1 and 5 where:

1 = Dissatisfied

2 = Slightly dissatisfied

3 = Neutral

4 = Slightly satisfied

5 = Satisfied

7: Reminders – Make sure to keep your permanent products associated with your outings and to take a photo of your activities when you go out!

- **What types of permanent products do you use to prove your activities? Write as many as you can think of (Write "Not Applicable" if you stayed in your home for the past three hours).**

Scenario 4

You went to a restaurant to have a lunch with your friend after the church service on Sunday. After the lunch, you stopped by at the Dairy Queen and got an ice cream corn at the drive-through. You left your home around 8:30am this morning and came back home around 12:30pm. You were satisfied because you got to hang out with your favorite friend and spent some fun time together.

Circle on the most appropriate answer.

1: Did you go out in the past three hours? Yes No

2: Where did you go in the past three hours?

Your choices are (check as many as apply):

- Car or bus *(either public or private)*
- Entertainment facility *(e.g., movie theater, bowling alley, zoo, theme park)*
- Grocery/Drug store *(e.g., Wal-mart, Dillons, CVS, Walgreens)*
- Gym/exercise facility
- Hospital/health care provider *(defined as hospital, doctor's office, rehab facility, dentist, etc.)*
- Home
- Office building *(defined as government or private. i.e. library, post office, bank)*
- Park/forest
- Public sidewalk
- Religious facility
- Restaurant/café/bar
- Retail store *(e.g. business establishment such as department store, mall, car dealer, coin laundry, gas station)*
- School *(university, community college, middle-school, high-school, etc)*
- Someone else's home
- Other

3: What kind of activity (or activities) did you engage in?

Your choices are (check as many as apply):

- Education *(e.g., taking classes, doing homework, on-line workshops/tutorials, reading textbook)*
- Employment *(defined as seeking, paid full-time work, paid half-time/hourly work)*
- Household/chores *(defined as housework, grocery shopping, childcare, household shopping, house improvements, meal preparation, paying bills, upkeep and maintenance)*
- Leisure *(defined as arts/culture, ceremony, club activity, computer, crafts/hobbies, gardening, games, playing music, talking on phone, reading, clothes shopping, sports, television)*

- Social *(e.g., chatting with friends, going to a party, attending, eating out with friends/family/peer/co-workers).*
- Self-care *(defined as exercise, grooming, medical appointments, other appointments, health related shopping)*
- Service/volunteering *(defined as unpaid work - e.g., babysitting friend's child)*
- Spiritual activities (*e.g., praying, attending faith service, meditating)*
- Resting *(defined as sleeping, napping, sitting quietly)*
- Transportation *(defined as driving, being a passenger, walking, wheeling, biking)*
- Other

4: Who did you primarily do this activity (or these activities) with?

Your choices are (check as many as apply):

- Alone
- Business person *(e.g., sales person, insurance agent, store clerk)*
- Personal care attendant
- Family
- Friends
- Mixed group
- Peers/Coworkers
- Pets
- Professionals
- Significant other (*defined as your spouse, partner, girl/boy friend)*
- Strangers
- Other

5: If you went out in the community, how long were you out?

Your choices are (Please choose only 1 answer):

- Less than 30 min.
- 30 min. to 1 hour
- 1-2 hours
- 2-3 hours
- N/A *(Not applicable – in other words, you did not go out in the community)*

6: On a scale of 1-5, how would you rate overall satisfaction with this (these) activity (activities)?

Tap the scale on a number between 1 and 5 where:

1 = Dissatisfied

2 = Slightly dissatisfied

3 = Neutral

4 = Slightly satisfied

5 = Satisfied

7: Reminders – Make sure to keep your permanent products associated with your outings and to take a photo of your activities when you go out!

- **What types of permanent products do you use to prove your activities? Write as many as you can think of. (Write "Not Applicable" if you stayed in your home for the past three hours)**

Scenario 5

You went to Hastings to rent a DVD around 6:30 pm. Shortly after you came back from the Hastings, you started cooking for dinner. After the dinner, you watched a DVD with your family. You were satisfied because you had a quality and relaxing night with family.

Circle on the most appropriate answer.

1: Did you go out in the past three hours? Yes No

2: Where did you go in the past three hours?

Your choices are (check as many as apply):

- Car or bus *(either public or private)*
- Entertainment facility *(e.g., movie theater, bowling alley, zoo, theme park)*
- Grocery/Drug store *(e.g., Wal-mart, Dillons, CVS, Walgreens)*
- Gym/exercise facility
- Hospital/health care provider *(defined as hospital, doctor's office, rehab facility, dentist, etc.)*
- Home
- Office building *(defined as government or private. i.e. library, post office, bank)*
- Park/forest
- Public sidewalk
- Religious facility
- Restaurant/café/bar
- Retail store *(e.g. business establishment such as department store, mall, car dealer, coin laundry, gas station)*
- School *(university, community college, middle-school, high-school, etc)*
- Someone else's home
- Other

3: What kind of activity (or activities) did you engage in?

Your choices are (check as many as apply):

- Education *(e.g., taking classes, doing homework, on-line workshops/tutorials, reading textbook)*
- Employment *(defined as seeking, paid full-time work, paid half-time/hourly work)*
- Household/chores *(defined as housework, grocery shopping, childcare, household shopping, house improvements, meal preparation, paying bills, upkeep and maintenance)*
- Leisure *(defined as arts/culture, ceremony, club activity, computer, crafts/hobbies, gardening, games, playing music, talking on phone, reading, clothes shopping, sports, television)*
- Social *(e.g., chatting with friends, going to a party, attending, eating out with friends/family/peer/co-workers).*
- Self-care *(defined as exercise, grooming, medical appointments, other appointments, health related shopping)*
- Service/volunteering *(defined as unpaid work - e.g., babysitting friend's child)*
- Spiritual activities (*e.g., praying, attending faith service, meditating)*
- Resting *(defined as sleeping, napping, sitting quietly)*
- Transportation *(defined as driving, being a passenger, walking, wheeling, biking)*
- Other

4: Who did you primarily do this activity (or these activities) with?

Your choices are (check as many as apply):

- Alone
- Business person *(e.g., sales person, insurance agent, store clerk)*
- Personal care attendant
- Family
- Friends
- Mixed group
- Peers/Coworkers
- Pets
- Professionals
- Significant other (*defined as your spouse, partner, girl/boy friend)*
- Strangers
- Other

5: If you went out in the community, how long were you out?

Your choices are (Please choose only 1 answer):

- Less than 30 min.
- 30 min. to 1 hour
- 1-2 hours
- 2-3 hours
- N/A *(Not applicable – in other words, you did not go out in the community)*

6: On a scale of 1-5, how would you rate overall satisfaction with this (these) activity (activities)?

Tap the scale on a number between 1 and 5 where:

1 = Dissatisfied

2 = Slightly dissatisfied

3 = Neutral

4 = Slightly satisfied

5 = Satisfied

7: Reminders – Make sure to keep your permanent products associated with your outings and to take a photo of your activities when you go out!

- **What types of permanent products do you use to prove your activities? Write as many as you can think of. (Write "Not Applicable" if you stayed in your home for the past three hours)**

Appendix M

Community Participation Activity Form

Community Participation Activity Form

	Where	What	With Whom	How Long	How Satisfied
Monday	1. 2. 3.				
Tuesday	1. 2. 3.				
Wednesday	1. 2. 3.				
Thursday	1. 2. 3.				
Friday	1. 2. 3.				
Saturday	1. 2. 3. 4. 5.				
Sunday	1. 2. 3. 4. 5.				

Appendix N

PDA Data Collection Feedback Session Script

PDA Data Collection Feedback Session Script

Participant's Name_____

Today's Date _____

Data Collection Period _____

*Start digital voice recorder at the start of the meeting.

Step 1: Acknowledging receipt of data and thanking the participant.

"I have downloaded your last set of data, thanks for entering it into the PDA."

Step 2: Commenting on amount of data entered

Option 1: "You responded to all (or almost all) of the prompts in between _____. Great job!

> "Out of _____ data entry points available for each week, you have accurately entered _____ data entries this week and only missed _____ times. You have an average of _____% completion rate so far. Keep up the good work!"

Option 2: "I know it is difficult to respond to all of the prompts, but you missed "_____" data points during the last data collection period. You have a completion rate of _____ % so far. I'd like to talk about what may have interfered with your data collection and do some problem solving…."

Note:

Step 3: Commenting on the number of permanent products and photos provided

> Option 1: "You saved/took all (or almost all) of the permanent products and photos associated with your outings. Thank you for doing a great job!"
>
> Option 2: "I know it is difficult to remember to save all of your permanent products and take photos during your outing. I'd like to talk about how you can improve these tasks."

Note:

Step 4: Asking questions about the data.

> "I have one (a few) questions about the data from our previous meeting." (Record questions here at time of download and inspection, which will be asked at the next meeting with participant).

Note:

Step 5: Asking questions about the permanent products and photos.

> "I have one (a few) questions about permanent products you submitted and/or photos you took since my last visit."(Record questions here at time of download and inspection, to be asked at the next meeting with participant)

Note:

Step 6: Providing information on their completion rate and reward amount

> "You have an average of _____ % completion rate so far. If you continue performing like this, you will receive _____ at the end of the study."

Step 6: Encouragement to continue participating, and date/time of next meeting.

> "Your participation in this study is very important to us and we appreciate your effort. I look forward to meeting with you to collect more data on…. _____"

"Do you have any questions I can help you with at this point?"

Comments:

*Stop digital voice recorder at the finish of the meeting.

Appendix O

Get Out & About! Training PowerPoint Presentation Slides

Note: Due to a size of this material, it is not included in the Appendix section. A copy of this material is available on the web at: https://documents.ku.edu/xythoswfs/webview/fileManager?stk=A0083F00D940683&entryName=%2Fusers2%2Fchiaki%2FChiaki+Gonda+Thesis+Materials&msgStatus=.

Appendix P

Get Out & About! Training Guidelines

General Training Guidelines/Protocol

The training consists of a Power Point Presentation, an individual/group exercises, and pre and posttests. Each chapter takes about 2 hours to go through and the whole training will last approximately 8 hours plus two 1-hour working lunch meetings. Training will be held over two consecutive days (2 chapters a day). Topics include: Goal Setting, Problem Solving, Information Seeking, and Advocacy.

1. *Greetings and Reflections*: The training facilitator will open a session with a greeting and reflection from the previous session This is to inform participants the beginning of a session and help them retain information and skills they learned in the previous session through verbal repetition.

2. *Provide the training overview and introduce the learning objectives:* At the beginning of each training session, the facilitator will give a brief overview of the training, learning objectives its rationale. This is to help identify expectations and target goals for the participants.

3. *Power Point Presentation*: The facilitator will deliver oral presentation using the power point slides. The facilitator will cover the key components from the manual and go over each point by explaining definitions and giving examples.

   Individual and group exercise: During the power point presentation session, the facilitator will ask participants to engage in the individual or group exercise. Individual and group exercises involve: open discussion, role-play and peer-tutoring. The facilitator will provide verbal reinforcers (i.e., good job, good example) and corrective feedback as needed.

4. *Wrap-up and summary of the training session*: The facilitator will go over the main objective and key take-away lessons from the training.

5. *Schedule (remind/confirm) for next training date/time*: The facilitator will remind participants about next training and any assignments for the next session.

6. *Post-Test*: The facilitator will administer a test after the training. (A pre-post had been already administered one week before the training).

   *Pre and Posttest is worth 65 points total.

   * If participants score less than 80%, the facilitator will go over the errors and teach the correct answers. Participants may leave the room when the facilitator calls for a closure of the session.

Appendix Q

Get Out & About! Training Checklist

Session 1: Introduction and Setting Goals

☐ Set up the PowerPoint presentation

☐ Greetings

☐ Introduction of the Training

- What's *Get Out & About!* Workshop?
- Why is community participation important?
- Guiding Principle
- Chapter Overview
- Rules and expectations

--- Start of the workshop 1 ---

☐ Chapter overview

☐ Goal Setting Information

- Quality of Life Goals
- Types of Goals

☐ Exercise 1: Write down small, medium and large accomplishments

- Section 1: Discussion of Goals
- Desires vs. Goals
- Quality of Life Basics
- Decide on a Personal Goal

☐ Exercise 2: My Favorite Things

- Section 2: Your Current Goals

- House of Living Well – Consider your foundations

☐ Discussion: Your Value and Priority

- Exercise 3: My Time Today and My Ideal Schedule – Where does my time go?
- Section 3: Your Future Goals
- Exercise 4: Favorite Movie & Story Boarding
- Deciding on Goals
- Goal linking
- Imagination of your goal
- Easier said than done
- Feeling hopeless?

☐ Section 4: Developing a SMART Goal Statement

- Selecting a realistic goal
- Jen's example
- SMART goals
- Turning desires into goals
- Write a goal statement
- Examples of Goals
- Exercise 6: Write a goal statement
- Developing Objectives and To-Do List
- What's objective?
- Example of objective statements
- What's to-do list?
- Examples of to do list
- Exercise 7: Pathway to Completion Worksheet

☐ Summary

☐ Questions

☐ Preview for Next Chapter

Session 2: Solving Problems

--- Start the workshop 1 ---

- Review Chapter 1

- Chapter Overview

    1. Identify the problems or barriers on the path to your goal.
    2. Choose the first step toward your goal.
    3. Notice and track personal progress toward reaching your goal.

- Guiding principles

- Problem Solving Introduction

    - About problem-solving
    - Peer Support

- Exercise 1: Problems and Peers

- Section 2: What's the problem?

- Planning a path to your goal
- Nagging health problems
- Jen's example
- Domino effect

- Exercise 2: List the Problems
- Section 3: Find a Good Starting Place

- Show stoppers
- Goal shifting and examples

- Exercise 3: The Path to Your Goal – Choose 3 problems to work on
- Section 4: Solving Problems
- Jen's example
- Solving problems
- Get fresh ideas
- Million dollars would help
- Fresh Ideas

- Exercise 4: Build and write the To-Do List
- Section 5: Getting started by paying attention

    - Paying attention to your time, health and progress

- Exercise 5: Your Goals and Your Health
- Exercise 6: Write weekly To Do List
    - Jen's example

☐ Review

☐ Summary

☐ Questions and Answers

☐ Reminder for next class/activities

- Next session topic, time and date
- Things to prepare for next time

--- The end of the workshop 1 ---

Session 3: Seeking Information

☐ Set up the PowerPoint presentation

☐ Greetings

--- Start of the workshop 2 ---

- Review the chapter 2

- Chapter overview

1. Identify your information needs.
2. Figure out where to find the information you need.
3. Collect and evaluate the information you find.
4. Take action using the information.

- Section 1: Why and when to seek information
    - Why seek information?
    - Toward meaningful participation
    - Example – accessibility
    - Types of Problems and changes
    - How to describe your needs
- Section 2: Collecting Information
    - Locate information sources
    - Pitfalls
    - Information Source Sheet
- Exercise 1: Fill in your own contact sheet
- Steps on Collecting Information
    - Choose your first contact wisely
    - Contact the sources most likely to have the needed information
    - Present your problem and request help
    - Ask for materials to study at home
    - Ask what other information sources might be useful
    - Keep collecting information until you're satisfied
    - Study and reflect on the information you've collected
- Section 3: Evaluating Information
    - Is the information understandable?
    - Is the information relevant?
    - Is the information contradictory?
    - Is the information timely?
- Section 4: Take action
    - Understand the risks and benefits of your choices
    - Making decision
    - Share information

☐ Summary

Session 4: Advocacy

- Introduction

Advocacy is speaking up for what you want. You have the right to make your own choices. However, sometimes you need the cooperation of others to get what you want. Advocacy skills can help you get cooperation from others needed to reach your goals.

- Chapter overview

1. Self-Advocacy
2. Group-Advocacy
3. Peer Support
4. Advocacy Steps
5. Advocacy Strategies
6. Advocacy Letter

- Review Section 1: Self-advocacy

- Complete exercise1: My advocacy steps and approach

- Review Section 2: Group Advocacy

- Review Section 3: Advocacy – The Pathway to Enlightenment and Action

- Review Section 4: The Action Letter Portfolio

- Complete Exercise 2: Write your own advocacy letter

☐ Summary

☐ Reflection

--- The end the workshop 2 ---

- Administer the Post-Test

Appendix R

Weekly Peer Support Meeting Script

Peer Support Meeting Script

Date _____ Time Started _____

Place_____ Time Ended _____

*Start digital voice recorder at the start of the meeting.

Step 1: Greetings.

“How are you? Thank you for coming!”

Step 2: Give a brief overview of the meeting.

- Today, we will talk about……
- Also we will briefly discuss……
- Then, we will wrap up by……..

Step 3: Discussion of progress, problems and/or barriers toward reaching a goal.

1. What specific steps have you taken to accomplish your goal since we last met?
2. What things went well to help you reach your goal?
3. What problems or barriers did you encounter?
4. What steps did you take to resolve the problems or barriers? What things as a support group can we do to help you to help think about how to resolve these problems?
5. Did you seek any type of information since we last met? If yes, please tell us the specific types of information for which you were looking.
6. What things went well to help you gain the information that you need?
7. Are you stumped or puzzled about what information you might need next or how to obtain this information? What things as a support group can we do to help you to help think about how what information you need and how to get it?
8. When is the deadline for seeking this information?
9. Have you done any type of advocacy since we last met? If yes, please tell us the specific types of personal actions you took to work toward achievement of your goal, objectives or action steps.

10. What things went well in helping you to self-advocate for yourself?
11. Are you stumped or puzzled about the type of advocacy you might need next to address your goal, objectives or action steps? What things as a support group can we do to help you to help think about appropriate advocacy steps you might take to make further progress?
12. Since the last time we met, please indicate the progress you made by completing the chart below. For example, how many goals or objectives or action steps did you achieve? Did you modify any of your goals, objectives or action steps? Or did you add any new goals, objectives or action steps since we last met?

	Achieved	**Modified**	**New**
Goals set			
Objectives			
Action Steps			

13. What specific things do you promise to do from your goals, objectives or action plan until we next meet? Let's review the to-do list.
14. Do you have any questions or concerns that you would like to discuss at this time?

4: Schedule time/place for the next peer support group meeting.

- "Thank you again for coming. I look forward to meeting with you next _____ at _____ _____."

(Date) (time) (place)

*Stop digital voice recorder at the end of the meeting.

Appendix S

Study 1 Social Validity Survey and Results

Study 1 Post-Intervention Social Validity Survey Responses

Training Workshop	**Mick**	**Don**
1. How would you rate the *Get Out and About!* Training Workshop?	5	4
2. How would you rate the content of the training?	3	3
3. How would you rate the organization of the training?	5	4
4. How would you rate the understandability of the training?	5	4
5. How would you rate the place/environment of the training?	5	4
6. How would you rate the length of the training?	3	4
7. How would you rate the pace of the training?	5	3
8. How would rate the trainer?	5	4
9. How did you like the goal setting chapter?	5	3
10. How did you like the problem solving chapter?	3	3
11. How did you like the information seeking chapter?	5	2
12. How did you like the advocacy chapter?	5	4

Training Manual	**Mick**	**Don**
1. How would you rate the *Get Out and About!* Training manual?	5	3
2. How would you rate the content of the training manual?	5	2
3. How would you rate the organization of the training manual?	5	4
4. How would you rate the understandability of the training	3	3

manual?		

Data Collection Procedure	**Mick**	**Don**
1. How would you rate the ease of PDA data entry process?	5	5
2. How would you rate the use of digital camera to track your community participation activities?	2	5
3. How would you rate the frequency of the PDA entry required for this study (four times a day, 7 days a week)?	5	3
4. How would you rate the ease of saving and submitting your permanent t products?	5	4
5. How would you rate the length took for completing each data entry?	5	4
6. How would you rate the researcher's performance to provide feedback at the data collection meeting?	5	5
7. How would you rate the researcher's ability to help with data collection procedure?	5	4
8. How would you rate the PDA training?	5	4
9. How would you rate the PDA Instruction Book?	5	3
10. How would you rate the helpfulness of the researcher's feedback?	5	3
11. How would you rate the amount of monetary reward set for this study?	5	3

Peer support Meeting	**Mick**	**Don**
1. How would you rate the overall experience in working with the weekly peer support meeting?	5	4
2. How would you rate the length of the peer support meeting?	5	4
3. How would you rate the content of the peer support	5	3

meeting?		
4. How would you rate the place/environment of the peer support meeting?	5	3
5. How would you rate the pace of the peer support meeting?	5	3
6. How would you rate the frequency of the peer support meeting?	5	3
7. How would you rate the helpfulness of the peer support meeting in reaching your goal?	5	5

Research Staff	**Mick**	**Don**
1. How would you rate the overall experience in working with the researcher?	5	4
2. How would you rate researcher's competency?	5	4
3. How would you rate the availably of researcher?	5	4
4. Did the researcher come to the meeting on time?	Yes	Yes
5. Did the researcher able to provide helpful feedback?	Yes	Yes
6. Did the researcher explain things in detail?	Yes	Yes

Overall Experience	**Mick**	**Don**
1. How would you rate the overall experience in the *Get Out & About!* training and research study?	5	3
2. Would you recommend this training to someone who has a similar disability?	Yes	Yes
3. What was most helpful about the study?	I was treated very well throughout training - my opinion was valued, respected. (Training) put me into more context, more people to interact.	Probably the most helpful thing was how to advocate for myself. If I should ever be in a position where I needed to force a change to be made to some or something that created an

		additional barrier for me to have to overcome. Hopefully I'll never need to.
4. What was least helpful about the study?	Didn't like taking pictures because of some negative comments/attitudes when taking pictures in stores.	Probably having to meet the schedule of the PDA entries. It was surprising how many times I needed to do some adjustments to my schedule for doing something. If there were a way to make entries a few minutes (?) or going out or even doing something at home, it would be a good thing. It might also be a good thing to perhaps be able to shift the entire forward or backward 30-60 minutes.
5. Do you think your ability to set goals has changed as a result of this study? If yes, what things are different?	I am more motivated to set goals. I know how to set them. My goals are more organized, attainable, and specific.	I don't think my ability to set goals has changed significantly.
6. Do you think your ability to solve program has changed as a result of this study? If yes, what things are different?	I make a list of things before I start working on the problems. I also know how to case out place and do some research before doing.	I think it may have caused me to slow down a bit and to spend more time to 'mull' the ramifications of my actions. This is significantly surprising to me.
7. Do you think your community participation style/pattern has changed as a results of this study?	It made me smarter, aware of my surroundings. It also made me conscious about what's out there (i.e., transportation).	I don't think I am doing any more or less in the community than I was before becoming involved. I do take more to considering possible ramifications now.

Appendix T

Study 1 Prepayment Product Check sheet

Reliability Checklist

The purpose of this reliability check is to compare the number of self-reported outing(s) with the number and types of permanent products submitted by each participant to verify their community participation activities. Please follow the instructions given by the researcher and complete the table below. Types of permanent products may include sales receipts, ticket stubs, church bulletins, brochures, medical appointment cards and/or photos. If present on the item, please record the date, time and address (name of place/business).

Observer: _____ Date: _____

Participant Name: _____

Date	Types of PP Submitted	Place of Outing	Date/Time on the PP

Appendix U

Study 1 Peer Support Session Reliability Scoring Sheet

Peer support Reliability Checklist

Observer:_____ Observation Date: _____

Instruction: Please listen carefully to the recorded social support meeting discussion. To the best of your ability, please write down the number and details of self-reported action steps completed by each participant.

Date of the meeting: _____

Dick's goal: To enroll in a weekly Tai-Chi class

1.

2.

3.

4.

5.

Mike's goal: To get a part-time job

1.

2.

3.

4.

5.

Appendix V

PDA Data Collection Feedback Session Reliability Scoring Sheet

Reliability Scoring Sheet

Observer: _____ Date: _____

PDA Data Collection Feedback Session

Instruction: In the table below, please indicate whether each of the topics was covered in the session by checking “observed” if the topic was covered and by checking “not observed” if the topic was not covered. Please write down any questions or comments in the “Notes” column

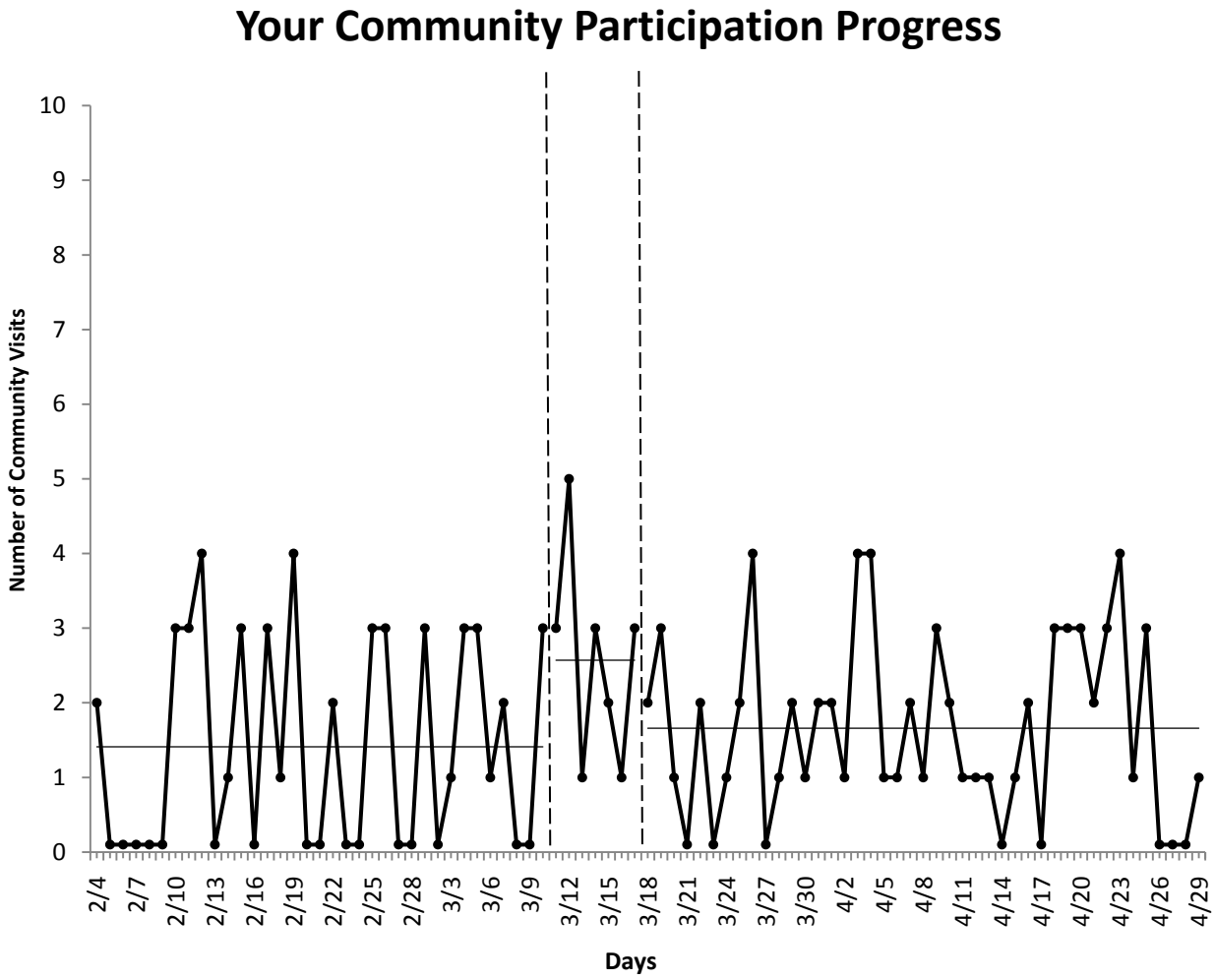
Meeting Date: _____

Participant Name: _____

Steps	**OBSERVED**	**NOT OBSERVED**	**Notes**
1. Acknowledged receipt of data and thanked the participant			
2. Commented on amount of data entered.			
3. Commented the permanent products provided.			
4. Asked questions about the data.			
5. Asked questions about the permanent products and photos.			
6. Provided information on their PDA completion rate and reward amount.			
7. Encouraged to continue participating, and set date/time of next meeting.			

Appendix W

Example of Visual Feedback/Progress Chart



Appendix X

Study 2 Baseline Data Collection Session Script

Baseline Data Collection Session Script

Participant's Name_____

Today's Date _____

Data Collection Period _____

Start digital voice recorder at the start of the meeting

Step 1: Acknowledging receipt of trip list and thanking the participant.

"Thank you so much for filling out the trip list".

Step 2: Ask questions about the list.

"I am going to ask you some questions to get more detailed information on each of your trip".

For each of the trip made, ask on the following information:

- Types of Location
  What kind of places was this? (i.e., entertainment facility, grocery store)
- Types of Activities
  What kind of activity would you say this outing was related to?
- Social Context
  Who did you go out with to this place?
- Duration
  Approximately, how long were you at this place?
- Satisfaction
  On a scale of 1-7, how satisfied were you with this activity/outing?

Step 3: Provide comments on the permanent products.

"Did you save any permanent products that were associated with your outings?"

If yes – "Thank you so much. Is it ok if I take these make a copy? I will return the original next week."

If no PP was saved – "If you get one next week, remember to save it for me, will you? If you lose or forget them, that's not a big deal!"

No outing – “Since you didn’t go out at all, obviously there is no permanent product for this week”.

Step 4: Ask any questions for concerns.

“Do you have any questions I can help you with at this point?”

Step 5: Encouragement to continue participating, and schedule a date/time of next meeting.

“I really appreciate you filling out the list and your participation in the study. Can I meet with you again on _____ at ____ am/pm? Great! See you on _____!” Thank you and have a great day!”

*Stop digital voice recorder at the finish of the meeting.

Appendix Y

Study 2 Recruitment Flyer

Want to know how you are doing with your community participation?

Enroll in a research study at Research and Training Center on Independent Living at the University of Kansas

If you enroll in a study you will:

- be asked to keep track of your daily activities
- be asked to meet with the researcher twice a week (at your home)
- receive monetary reward up to $300 for participating in the research study

Eligibility - Individuals with physical disabilities who meet ALL the criteria below:

- have a mobility related disability as a primary disability
- are between age 18-65
- are living in the community (not a group home/institution)
- can commit up to a 8-12 week study
- are not presently working in a full-time job

(*Your participation will be determined after a phone interview and a meeting with the research staff)

If you are interested in participating in this study, please call Chiaki Gonda, graduate research assistant, at 785-864-4095 or email at chiaki@ku.edu

Appendix Z

Study 2 Consent Form

Second Study

INFORMED CONSENT STATEMENT

Name of the Study

An Evaluation of Ecological Momentary Assessment to Measure and Increase Community Participation of People with Mobility-Related Disabilities

INTRODUCTION

The Department of Applied Behavioral Science at the University of Kansas supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you wish to participate in the present study. You may refuse to sign this form and not participate in this study. You should be aware that even if you agree to participate, you are free to withdraw at any time. If you do withdraw from this study, it will not affect your relationship with this unit, the services it may provide to you, or the University of Kansas.

PURPOSE OF THE STUDY

The purpose of the second study is to evaluate the effects of a PDA self-monitoring device and the use of publicly posted progress chart on increasing community participation of people with mobility-related disabilities.

LENGTH OF THE STUDY

The length of this study is expected to last between 8-12 weeks.

PROCEDURES

This section will explain what you will be asked to do if you enroll in the study.

Weekly Trip list

You will be asked to record the names of places you visited in the past week on a piece of paper. The researcher will visit your home each week and talk to you about your weekly trip list. As part of this study we would like for you to retain items from your trips into the community such

as receipts, tickets, and medical appointment cards if you are able. We will provide an envelope for you for these items.

Personal Digital Assistant (PDA)

You will be provided a personal digital assistant (PDA) device about the size of a pocket calculator, during the study and will be asked to carry the PDA with you wherever you go. Before you start using it, you will be taught how to operate the PDA. The researcher will come to your house to collect data each week.

- The PDA will make a gentle sound and prompt you four times each day at 12pm, 3pm, 6pm and 9pm.
- At each prompt, you will be expected to access to the PDA and enter answers to several questions
- It will take about one minute to answer the questions
- Upon completion of study, the PDAs will be returned to the researcher.

Later in the study, the researcher will meet with you to talk about your community outings and you will be asked to display your community outings on a piece of paper, where you can see it. The researcher will talk about your outing for that week to find out how things went.

RISKS

We don't anticipate any burdens, inconveniences, pain, discomforts or risks to be associated with participation in the study.

BENEFITS

Participants might be more likely to participate in community activities.

PAYMENT TO PARTICIPANTS

You will have an opportunity to earn up to $200. The amount of monetary reward you can receive will be determined by your PDA survey completion rate and length of your participation in the study. The money you earned will be paid at the end of the study or if you must withdraw from the study.

If your PDA completion rate is more than 90% throughout the study, you will receive the full amount $ 300. If your PDA completion rate is between 70-89%, you will receive half of the amount $150. If your PDA completion rate is below 70%, you will receive one-forth of the amount $75. (See chart below)

Payment Chart

PDA completion rate	90%-100%	70%-89%	Below 70%
Main Study	$300	$150	$75

If you decide to withdraw from the study or stop attending the scheduled meetings and/or performing assigned tasks, your monetary rewards will be re-calculated and adjusted based on the number of weeks you have completed, and your PDA completion rate during the weeks you participated.

You will be asked to complete some brief paperwork to fill out and you will need to give your social security number in order for us to issue payment.

PARTICIPANT CONFIDENTIALITY

Your name will not be associated in any way with the information collected about you or with the research findings from this study. The researcher(s) will use a study number or a pseudonym instead of your name. The researchers will not share information about you unless required by law or unless you give written permission.

REFUSAL TO SIGN CONSENT AND AUTHORIZATION

You are not required to sign this Consent and Authorization form and you may refuse to do so without affecting your right to any services you are receiving or may receive from the University of Kansas or to participate in any programs or events of the University of Kansas. However, if you refuse to sign, you cannot participate in this study.

CANCELLING THIS CONSENT AND AUTHORIZATION

You may withdraw your consent to participate in this study at any time. You also have the right to cancel your permission to use and disclose information collected about you, in writing, at any time, by sending your written request to: [Chiaki Gonda, Graduate Research Assistant, Research and Training Center on Independent Living, University of Kansas, 1000 Sunnyside Avenue, Dole Center, Room 4089, Lawrence, KS 66045]. If you cancel permission to use your information, the researchers will stop collecting additional information about you. However, the research team may use and disclose information that was gathered before they received your cancellation, as described above.

QUESTIONS ABOUT PARTICIPATION

Questions about procedures should be directed to Chiaki Gonda listed at the end of this consent form. Her contact information is listed at the end of this consent form.

PARTICIPANT CERTIFICATION:

I have read this Consent and Authorization form. I have had the opportunity to ask, and I have received answers to, any questions I had regarding the study. I understand that if I have any additional questions about my rights as a research participant, I may call (785) 864-7429 or (785) 864-7385 or write the Human Subjects Committee Lawrence Campus (HSCL), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7563, email mdenning@ku.edu.

I agree to take part in this study as a research participant. By my signature I affirm that I am at least 18 years old and that I have received a copy of this Consent and Authorization form.

_____ _____

Type/Print Participant's Name Date

_____

Participant's Signature

I also agree to be audiotaped during the weekly meetings with the researcher.

_____ _____

Type/Print Participant's Name Date

_____

Participant's Signature

Researcher Contact Information

Chiaki Gonda
First Investigator
Dept. of Applied Behavioral Science
4089 Dole Bldg
1000 Sunnyside Ave.
University of Kansas
Lawrence, KS 66045
785 864 4095
chiaki@ku.edu

Glen W. White, Ph.D.
Faculty Supervisor
Dept. of Applied Behavioral Science
4089 Dole Bldg
1000 Sunnyside Ave.
University of Kansas
Lawrence, KS 66045
785 864 4095
glen@ku.edu

Appendix AA

Study 2 Visual/Oral Feedback Session Script

Visual/Oral Feedback Session Script

Participant's Name_____

Today's Date _____

*Start digital voice recorder at the start of the meeting.

Step 1: Presenting the graph on a number of daily community visits (frequency data) and explaining what's on the graph.

"This graph shows you how you are doing with your community participation. The Y axis shows a number of community visits and the X axis shows you days. So let's go through this graph together. "

- During the last data collection period you had a total of __ outings in the community. You made __ less/more outing(s) compared to the last data collection period.

- Your community visits ranged from 0 - __. During the last data collection period, it was 0 -__.

- You have __days of non-outing during the last data collection period. Before that it was __.

Step 2: Asking participants about the graph.

Do you have any questions about these charts? If so, what's not clear to you?

Step 3: Asking a participants to post the graph.

1st time - "Can you please put this chart on the place where you can see every day such as refrigerator, entrance door, living room? Where do you choose to post this chart?

2nd time – “Can you please put this chart on _____ top of the graph I gave you last time we met?”

*Ask whether a participant needs a help with posting the chart.

Step 4: Asking participants about barriers and facilitators to their community participation.

1. By looking at these charts, how do you feel about your community participation? Do you think you are satisfied with this week’s results or do you think you can do more?

2. Did you face any barriers or problems that have kept you from going out to the community? If yes, what were they? (e.g., health problem, weather, accessibility, financial issues, etc.)

3. Did you encounter any facilitators (things that helped you participate more) when you were out in the community? What things went well and how did they help you?

4. Are there new activities or places you want to try to visit this coming week?

*Stop digital voice recorder at the finish of the meeting.

Appendix AB

Follow-up Visits Questions

Follow-up Visits Questions

1. Have you gone out to the community in the past eight days? If so, can you tell me more about your outings?

    - How many times did you go out this week?
    - Types of Location

        - Where did you go to when you went out? (i.e., entertainment facility, grocery store)

    - Types of Activities

        - What kind of activities did you do when you went out this past week?
        - Social Context
        - Who did you go out with when you went into the community?

    - Duration

        - Approximately, how long did you go out on each specific outing you described above?

    - Satisfaction

        On a scale of 1-7, how satisfied were you with these activities/outings?

May 4th (Wednesday)	May 5th (Thursday)
May 6th (Friday)	May 7th (Saturday)
May 8th (Sunday)	May 9th (Monday)
May 10th (Tuesday)	May 11th (Wednesday)

2. It's been two weeks since we completed the formal data collection on your community participation. Did you notice any difference in terms of awareness or motivation to get out more in the community? If so, what is the difference?

3. What things have changed in the past two weeks? Are there any personal factors or environmental factors that have changed since we last met?

4. Did you face any barriers that have kept you from going out to the community?

5. Did you face any facilitators when you were out in the community? What motivated you to get out in the community? Put another way, "What made you to go out and do stuff?"

6. Are there any new activities or places you are planning on doing or going to in the next 2-3 weeks?

Qualitative Interviews

- Types of services/benefits they receive (SSDI, Food stamp, public housing)

- Number of close friends/family members

- How often do you meet with each of those people?

- Closeness/connectedness to their neighbors and community members (on a scale of 1-5)

  1 = Very disconnected

  2 = Disconnected

  3 = Neither disconnected or connected

  4 = Connected

  5 = Very connected

- What's the meaningfulness of community participation? What does it mean to participate?

Appendix AC

Social Validity Survey and Results

Study 2 Post-Intervention Social Validity Survey Responses

Data Collection Procedure	Mark	Carmen	Lilly
1. How would you rate the ease of PDA data entry process?	5	4	4
2. How would you rate the frequency of the PDA entry required for this study (four times a day, 7 days a week)?	3	3	4
3. How would you rate the ease of saving and submitting your permanent t products?	4	3	5
4. How would you rate the length took for completing each data entry?	5	4	5
5. How would you rate the researcher's performance to provide feedback at the data collection meeting?	5	4	5
6. How would you rate the researcher's ability to help with data collection procedure?	5	4	5
7. How would you rate the PDA training?	4	4	4
8. How would you rate the PDA Instruction Book?	4	4	3
9. How would you rate the helpfulness of the researcher's feedback?	4	3	5
10. How would you rate the amount of monetary reward set for this study?	4	4	5

Visual/Oral Feedback	Mark	Carmen	Lilly
1. Was the visual feedback (chart) helpful in keeping track of your community participation progress?	Yes	No	Somewhat

2. Was the oral feedback helpful in identifying barriers/facilitators to your community participation?	Yes	Yes	Somewhat
3. Was the researcher mindful about your readiness and situation when planning your community participation activities?	Yes	Yes	Yes
4. Did the researcher explain thoroughly what's on the chart?	Yes	Yes	Yes

Research Staff	**Mark**	**Carmen**	**Lilly**
1. How would you rate the overall experience in working with the researcher?	5	5	5
2. How would you rate researcher's competency?	5	5	5
3. How would you rate the availably of researcher?	5	5	5
4. Did the researcher come to the meeting on time?	Yes	Yes	Yes
5. Did the researcher able to provide helpful feedback?	Yes	Yes	Yes
6. Did the researcher explain things in detail?	Yes	Yes	Yes

Overall Experience	**Mark**	**Carmen**	**Lilly**
1. How would you rate the overall experience in the research study?	4	3	4
2. Would you recommend this research study to someone who has a similar disability?	Yes	Yes	Yes
3. What was most helpful about the study?	It let me know how active I was.	Looking at the good side of facilitators and other people	Chiaki's warmness and very ability to explain the

		who were helpful when I was out in the community.	survey. Her abilities to make clear what the survey was for and how the survey would assist others in the future. We all have to work together in order to make life better and equal and just as the able bodied do now in the U.S. But most of all I loved working with Chiaki. She has become a friend.
4. What was least helpful about the study?		The charts were not that useful to me.	The charts. I am not a math wiz. Sorry!
5. Do you think your community participation style/pattern has changed as a result of this study?	Perhaps a little. I am more aware of what I do.	Yes, it helped me to get out in the community more especially since the tickets to do things in the community were paid by the research dept. Thank you!	
6. Any other comments or thoughts?			

Appendix AD

Study 2 Reliability Scoring Sheets

Baseline Reliability Scoring Sheet

Observer: _____ Date: _____

Collecting a Trip List

Instruction: In the table below, please indicate whether each of the steps was covered in the session by checking “observed” if the topic was covered and by checking “not observed” if the topic was not covered. Please write down any questions or comments in the “Notes” column

Meeting Date: _____

Participant Name: _____

Steps	**OBSERVED**	**NOT OBSERVED**	**Notes**
1. Acknowledged receipt of weekly trip list and thanked the participant.			
2. Asked questions about the weekly trip list (e.g., location, activity type, social context, duration, satisfaction).			
3. Collected permanent products or acknowledged receipt of the PP.			
4. Asked for questions or concerns.			
5. Encouraged to continue participating and scheduled a date/time of next meeting.			

Reliability Scoring Sheet

Observer: _____ Date: _____

PDA Data Collection Meeting Feedback

Instruction: In the table below, please indicate whether each of the topics was covered in the session by checking "observed" if the topic was covered and by checking "not observed" if the topic was not covered. Please write down any questions or comments in the "Notes" column

Meeting Date: _____

Participant Name: _____

Steps	**OBSERVED**	**NOT OBSERVED**	**Notes**
1. Acknowledged receipt of data and thanked the participant			
2. Commented on amount of data entered.			
3. Commented the permanent products provided.			
4. Asked questions about the data.			
5. Asked questions about the permanent products and photos.			
6. Provided information on their PDA completion rate and reward amount.			
7. Encouraged to continue participating, and set date/time of next meeting.			

Reliability Scoring Sheet

Observer: _____ Date: _____

Feedback Session

Instruction: In the table below, please indicate whether each of the topics was covered in the session by checking “observed” if the topic was covered and by checking “not observed” if the topic was not covered. Please write down any questions or comments in the “Notes” column

Meeting Date: _____

Participant Name: _____

Steps	**OBSERVED**	**NOT OBSERVED**	**Notes**
1. Presented the graph on participant’s community participation progress and provided a summary of the graph.			
2. Asked participants if they had any questions about the graph.			
3. Asked a participant to post the graph.			
4. Asked a participant about barriers and facilitators to community participation.			
5. Asked a participant about new activities or places he/she wants to try or to visit this coming week.			